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THE COMMONWEALTH OF MASSACHUSETTS

**DEVELOPMENTAL
DISABILITIES
COUNCIL**

GOVERNMENT DOCUMENTS
COLLECTION

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Annual Report

FEDERAL
FISCAL
YEAR

1994

(October 1, 1993 - September 30, 1994)

Massachusetts Developmental Disabilities Council

600 Washington Street - Room 670

Boston, Massachusetts 02111

(617) 727-6374

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CHAIRPERSON

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GOVERNOR

ANNUAL PROGRAM PERFORMANCE REPORT
FEDERAL FISCAL YEAR 1994

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WE GRATEFULLY ACKNOWLEDGE
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OF MIKE RIPPLE.

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I. IDENTIFICATION DATA

1. State: **MASSACHUSETTS**
2. Federal Fiscal Year Reporting: 1994
(October 1, 1993 - September 30, 1994)
3. State Council:

**MASSACHUSETTS DEVELOPMENTAL
DISABILITIES COUNCIL
600 Washington Street, Room 670
Boston, Massachusetts 02111-1704
(617) 727-6374
(617) 727-1885 (TDD)
FAX (617) 727-1174**

4. Designated State Agency:

**ADMINISTERING AGENCY for
DEVELOPMENTAL DISABILITIES
600 Washington Street, Room 670
Boston, Massachusetts 02111-1704
(617) 727-4178**

5. The Designated State Agency does not provide direct services.
6. Name of Preparer: **Jody Williams**
Telephone Number: (617) 727-6374 x. 110

II. REPORTING YEAR (FFY 1994)

BACKGROUND REGARDING DD STATE PLAN PRIORITY AREAS, GOALS, AND OBJECTIVES

The federal DD Act asks state Councils to "package" their major categories of concentration in "priority areas." The version of the Act in effect throughout most of the 1992-94 State Plan period was P.L. 101-496. The Act required one priority (Employment Activities) and suggested several other possible federal priority areas from which state DD councils could choose: Community Living, Case Management, Child Development, and System Coordination and Community Education. The reauthorized version of the DD Act, P.L. 103-230, signed by President Clinton in April 1994, did not change the priorities in effect during the 1992-94 State Plan cycle.

The Massachusetts Council, via its planning process, had in 1991 selected two federal priority areas for the three-year planning cycle covering Federal Fiscal Years (FFYs) 1992-1994:

- *Employment* (required federal priority)
- *System Coordination & Community Education* (optional federal priority selected by Mass. Council)

As defined in the DD Act, the term "employment activities" refers to activities "as will increase the independence, productivity, or integration of a person with developmental disabilities in work settings."

The term "system coordination and community education activities" means activities that:

- (A) eliminate barriers to access and eligibility for services, supports, and other assistance,
- (B) enhance systems design and integration including the encouragement of the creation of local case management and information and referral statewide systems, and
- (C) enhance individual, family and citizen participation and involvement.

P.L. 101-496, Section 102 (27)

Both versions of the DD Act in effect during FFY 1994 also require that Councils describe their intentions in the form of one or more general goals and specific plan-year objectives, for each three-year cycle and in each year's annual state plan. In the interests of simplicity and clarity, the Council articulated a single goal for its work throughout the 1992-1994 plan cycle:

1992-94 STATE PLAN GOAL

TO PROMOTE INDEPENDENCE, PRODUCTIVITY, AND INTEGRATION among all people with developmental disabilities through advocating for the maintenance and further development of INDIVIDUAL AND FAMILY SUPPORTS.

As in the two preceding years, eight objectives for plan year 1994 were chosen as targeted areas through which we would work toward our goal. Each objective included several specific activities which were selected, then undertaken, to help reach our goal. Activities utilized one or more kinds of DD program resources: (a) people involved directly with the Council, including Council members, committee members, and staff; and (b) grant project resources, including the Administering Agency, grant monies, and numerous grantee agencies, staff and volunteers. Numerous strategies were utilized by Council and grantee participants.

The following, Section II.A. #s 1-8, describes the major activities and accomplishments connected with the eight objectives undertaken during FFY 1994 (October 1, 1993 through September 30, 1994), in a format recommended by the federal Administration on Developmental Disabilities (ADD). ADD, within the U.S. Department of Health and Human Services, administers not only the DD Councils nationwide, but also the DD "protection and advocacy," "university affiliated," and "grants of national significance" programs.

We recommend reading this annual program performance report in conjunction with the Council's 1994 D.D. State Plan, available upon request to the office. The more recent 1995-97 State Plan, which makes some changes in priorities and objectives for the new three-year period which began on October 1, 1994, is also available.

For a list of the Council members active in FFY 1994 -- the hard-working volunteers appointed by Governor Weld -- kindly see the Appendix.

Please contact the office for any other information you desire. We are eager to involve all interested persons in the Council's work.

II. A. OBJECTIVES

OBJECTIVE #1 Family Support

1. Name and description of objective:

To promote a mandate for an entitlement to high quality family support services...work toward state legislation...support families to articulate their needs and desires, and bring to the Council as appropriate; share information...and sponsor and monitor innovative quality services which enable families to support, empower, and train each other.

2. Goal:

To promote independence, productivity, and integration among all people with developmental disabilities through advocating for the maintenance and further development of individual and family supports.

3. Extent to which objective has been met:

Largely

4. 1994 Expenditures for this objective:

A.	Federal:	\$30,000		Educate Parents as
	Match:	<u>10,000</u>		Policymakers/Year 3
		\$40,000	TOTAL	
B.	Federal:	\$90,000	(Year 2)	Family Support/
	Match:	<u>19,042</u>	(Poverty)	Multi-Cultural
		\$109,042	TOTAL	
C.	Federal:	\$10,000		Public Awareness
	Match:	<u>5,187</u>		Projects
		\$15,187	TOTAL	

5. Priority area:

System Coordination and Community Education

- 6. Classes of activities that were pursued for meeting the objective:**
- Activity to increase capacities and resources of entities for improved service delivery to persons with developmental disabilities.
 - Study or analysis
 - Development of model policies and procedures
 - Presentation (formal or informal to policy makers)
 - Training for access to or for provision of service
 - Other similar activity to prevent developmental disabilities or to increase independence, productivity and integration
 - Gathering information
 - Outreach activity

- 7. Kindly see next page for summary of this objective's activities and accomplishments.**

OBJECTIVE # 1 Family Supports

Summary of Accomplishments

The Family Support Steering Group, a Council committee, was responsible throughout the 1992-94 cycle for activities in this area.

• ENCOURAGING GRASSROOTS FAMILY ORGANIZATIONS AND PROMOTING STATE FAMILY SUPPORT LEGISLATION

Educate Parents as Policymakers Project

Using DD funds, Human Services Research Institute (HSRI) worked for a third year to support Families Organizing for Change (FOC), a grassroots organization of family members of people with disabilities. FOC has gained statewide vitality as regional groups have started to take root in Central Massachusetts and on the North Shore (with Boston following suit). The more-established groups in Southeastern and Western Massachusetts have conducted family leadership training series for several years; in FY 1994, the Central and North Shore groups started their first family leadership trainings, and Boston plans to start in 1995. For the first time in 1994, FOC members obtained some funds from the Dept. of Mental Retardation (DMR) for leadership training: DMR intends to continue its commitment in 1995, and the Department of Public Health has also made a small commitment.

Staff and FSSG members have continued their close working relationship with FOC. Council representatives attended FOC steering committee meetings, promoted the Citizen Support legislation (the Council's priority bill) via mailings, testimony, and State House visits; provided fact sheets about human services in different languages for local FOC activities; and helped members of FOC to meet people from various DD-funded projects in Family Supports, Multi-cultural Outreach, and Legislative Advocacy Training to enrich training and other opportunities for them.

Staff ensured that HSRI's survey questionnaire on "Quality Family Supports to Families" was shared with several key groups in Massachusetts, i.e. the Family Support Steering Group, the Department of Mental Retardation, Early Intervention programs and parents, and participants at the Personal Care Assistance Forum.

"Putting the POWER in Empowerment" Conference

A DD small grant funded a FOC member agency to conduct a "Putting the POWER in Empowerment" conference in Worcester in September 1994. The 150 family members who attended included some Latino and African American family members, the result of connections with other Council-funded projects in the Multi-Cultural area. There was a lot of energy, and Secretary Baker of the state's Executive Office of Health and Human Services confirmed his support of FOC's and the Council's top legislative priority, the Citizen Support bill.

Citizen & Family Support Legislation

FOC has filed legislation to "Support Citizens with Disabilities and Their Families" for three years. Despite FOC's work with administration leaders, a fiscal analyst of the House Ways and Means Committee, and a key state representative to promote passage of the bill, and the support of the Council and other advocates, the bill has not yet passed. (FSSG has supported the bill for three years, and it has been the Council's priority bill in 1993 and 1994.) It will be re-submitted for the 1995 Legislative Session. Please consult the Public Policy section, Objective #4, for more information.

Joint Family Support/Multi-Cultural Project to disseminate the philosophy of family support

The Council's 1990 Report, Creating Open Communities, recommended entitlement to family support services and outreach to cultural and linguistic minorities. The Family Support/Multi-Cultural Project, conducted by New North Citizen's Council and the Martin Luther King Jr. Center, targets families in Hispanic and African-American communities in the western part of the state to educate them about family support services, how to increase their access to services, and to provide them with the opportunity to participate in the growing "family support movement." The grant started in the fall of 1993, with a member of Families Organizing for Change involved from the beginning. FFY 1994 DD monies are funding the second year of implementation, which began in the fall of 1994.

In the first year, the grantee: provided intensive staff training in disability; identified and recruited consumers and family members; developed a focus group to bring consumers and family members together for support and program development; brought staff, consumers, and family members together to trainings in developmental disabilities, self-advocacy, family support, and disability awareness; developed a resource library and a community based resource directory for people with disabilities and their families; and hosted a DD FS family gathering. By the end of the year, the Project had served 32 family members. Since June 1994, consumers and family members attended 12 educational and training events, including the "Families Have Choices" event in Boston. In addition, project staff and a parent presented at the "Celebrating Individual and Family Support" conference in Western Massachusetts in June 1994.

• "FAMILIES HAVE CHOICES": FOLLOW-UP TO CASH ASSISTANCE PROJECT

Since the end of the Council's three-year Family Cash Assistance Project in December 1992, the Council has disseminated both the final report and the separately-conducted evaluation, and project staff have given talks on cash assistance throughout the state and in New York. In addition, DMR has been quietly implementing more flexible respite care programs as well as some pilot voucher and cash assistance programs for the last few years.

In order to promote the "cash assistance" idea, the FSSG decided to work with other organizations to plan "Families Have Choices," an event in Boston to inform families about flexible family supports, including cash assistance. The planning group included FSSG members, staff from several local providers of human services, representatives of the university affiliated programs, the Disability Law Center, and DMR's Boston Regional Office, advocates, a representative of Families Organizing for Change, and staff members from three providers which serve Latino, Haitian, and Chinese populations. Each organization publicized the event and donated money and/or staff time; the Council contributed \$1500, about one-half the costs, from FSSG's public awareness funds.

People were impressed not only by the good attendance, but also by the diversity of the participants and the cooperation of the various sponsoring agencies. Over one hundred family members, including Latinos, Haitians, African Americans, Caucasians, and Chinese, participated. Transportation, translation services, and on-site respite care were available and were used. Welcomes were made by the MDDC and FSSG chairs, a Haitian parent, a Latino service provider, DMR staff, and a Boston provider. The morning panel included family members, two of whom had been served by the Council's Family Cash Assistance Project, a provider, and Valerie Bradley of Human Services Research Institute. After participating in small groups in the afternoon, family members then met with the Director of DMR's Boston Regional Office and with an attorney from the Disability Law Center.

● PUBLIC AWARENESS

The FSSG reserved a pool of 1994 money to promote public awareness by helping fund events which came to the Committee's notice. In addition to the "Families Have Choices" event, we:

(1) Sponsored 12 consumers to attend the American Association on Mental Retardation Conference in Boston. (Many of these people, including a Latino parent, attended an AAMR event for the first time.)

(2) Helped fund via the Children's Network 1994, an Information/Resource Fair in Watertown for families with children with special needs.

(3) Funded Phase II of "Operation House Call," to publicize the Project, which promotes the sensitivity of medical students to issues families with members with disabilities face day to day. See a complete description of three projects on medical sensitivity training in section II B, below, on "Innovative Activities."

(4) Co-sponsored Children's Advocacy/Youth Empowerment Day in May 1994 at the State House on issues of concern for children and adolescents. The Council was a "champion sponsor" and a teen with disabilities was included on the panel of presenters.

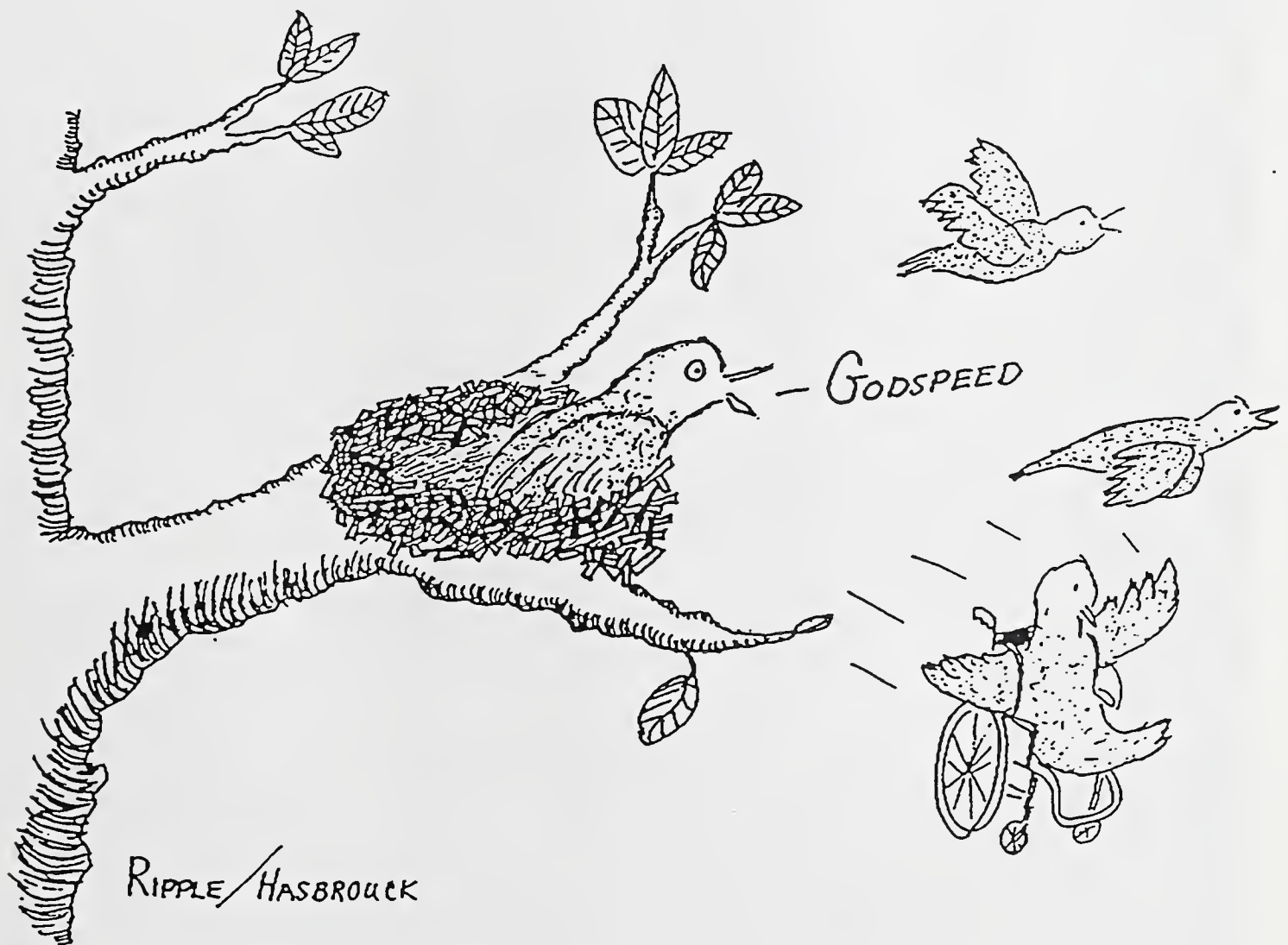
(5) Provided disability-related materials for a Boston Prevention

Day in early May 1994, to support the Department of Public Health's emphasis on prevention of disabilities.

Other Issues and Advocacy

Members of the FSSG served on a joint Council committee with IPI members to work on Personal Care Assistance issues with the Human Services Research Institute. More information on PCA activities is in Objective #2, on Independence, Productivity, and Integration.

Concerned about services for children in the child welfare system, the FSSG contacted the state's Department of Social Services (DSS) in regard to its new federal family preservation project; and we have consistently advocated for more flexible financial criteria for families with children with disabilities for state-subsidized care funded through the Child Care and Development block grant. Recently, we commented on a proposed Management Information System for subsidized day care to the Executive Office of Health and Human Services, stressing the need for involvement and coordination with Head Start, early education programs, and the Early Intervention system.



OBJECTIVE #2 Supports for Integrated Living and Working

1. Name and description of objective:

To increase the network of supports available to and directed by persons with disabilities, to enable them better to live, work, learn and play in their communities.

2. Goal:

To promote independence, productivity, and integration among all people with developmental disabilities through advocating for the maintenance and further development of individual and family supports.

3. Extent to which objective has been met:

Largely.

4. Expenditures for this objective:

A. Federal:	\$25,000	Citizens Housing &
State:	<u>15,832</u>	Planning Assn. (CHAPA)
	\$40,832	

B. Federal:	\$25,000	N.E. INDEX/Shriver Center
Match:	<u>92,370</u>	
	\$117,370	

5. Priority area:

Employment. System coordination and community education.

6. Classes of activities that were pursued for meeting the objective:

- Activity to increase capacities and resources of entities for improved service delivery to persons with developmental disabilities
- Study or analysis
- Gathering information
- Outreach activity
- Presentation (formal or informal to policy members)
- Training for access to or provision of service
- Other similar activity to prevent developmental disabilities or to increase independence, productivity and integration
- State Plan development
- Activity addressing the implementation of 1990 Report findings
- Coordinating activity other than above (commenting on other State Plans, State ICF/MR actions, unserved/underserved, other)

7. Kindly see next page for summary of this objective's activities and accomplishments.

OBJECTIVE #2 Supports for Integrated Living and Working

Summary of Accomplishments

The Council's Integration/Productivity/Independence (IPI) Committee had primary responsibility for implementing this objective throughout the 1992-94 DD State Plan cycle. To increase the involvement of consumers in its activities, the Committee continued to work in three subcommittees: **Employment, Personal Assistance Services, and Housing.**

The Employment Subcommittee accomplished the following:

As in 1993, IPI Committee members and staff monitored the implementation of the amendments to the Rehabilitation Act through its participation as members of the Massachusetts Rehabilitation Commission (MRC) State Advisory Board (SAC) and the Statewide Independent Living Council (SILC). Particular attention was paid to the structure and functions of those two bodies that are being changed to comply with the Act: the Statewide Independent Living Council and the Rehabilitation Advisory Council (RAC). Some of the IPI Committee members and staff are waiting for confirmation of their appointments to the SILC and MRC's SAC. Members of the IPI Committee and staff commented on the vocational rehabilitation (VR) plans of both MRC and the Massachusetts Commission for the Blind (MCB), as well as the independent living plan of the IL Council. Budget advocacy was successful in maintaining level state funding although the VR waiting list continues to grow due to the lack of sufficient funds to meet the demand. Present waiting list duration is nine to twelve months.

In the area of supported employment, the IPI Committee was successful on several fronts. A Supported Employment Task Force consisting of MDDC, the Dept. of Personnel Administration (DPA), the Governor's Commission on the Employment of Persons with Disabilities (GCEPD), and the Office of Employment Services (OES-MRC) was formed by the IPI planner to design a pilot project. The purpose of this pilot is to implement a small supported employment program within state government, which would allow the Commonwealth as an employer to test the best ways to offer supports to staff with severe disabilities. The MDDC will continue this project into the 1995-97 state plan cycle.

As the result of the supported employment strategic planning done in 1993 and 1994, the Employment Services Action Council (ESAC) was formed in the spring of 1994. Its first task was to apply for a "systems change" grant from the U.S. Dept. of Education, to develop a single point of entry and enhance consumer choice empowerment in accessing and receiving services. This three-year grant was awarded to the Office of Employment Services in MRC as the lead agency, and started Oct. 1, 1994. ESAC was also successful in establishing a cooperative and pro-active working relationship with the Dept. of Employment and Training (DET) to enable DET to become

more inclusive of persons with disabilities in their services. The MDDC will continue its participation in ESAC and the activities of the "systems change" grant in its next planning cycle.

In FFY 1992, the DD Program initiated a three-year \$75,000 grant to Work, Inc., to develop and implement a pilot project for technical assistance to consumers and (when appropriate) their families, advocacy organizations and providers in accessing and using Social Security's Plan to Achieve Self Support (PASS) program. FFY 94 marked the final year of DD funding for this project. Although detailed statistics are not available until the final report, the projects's assistance to consumers and their families resulted in a significant increase in the numbers and quality of Social Security-approved PASS plans in Massachusetts. Having concluded that assistance with PASS plans should be a standard service in the state, Work, Inc. will recommend how this service should be provided. In FFY 95, the Council's Employment Committee will review these recommendations and advocate that PASS assistance provisions be required of all private non-profit vocational rehabilitation vendors.

The Personal Assistance Services (PAS) Subcommittee accomplished the following:

As outlined in the past two annual reports, eligibility for Personal Care Assistance (PCA) services continues to be negatively impacted by the changes made in the state Medicaid program's 1992 administrative guidelines. Because Medicaid still regards PCA as a service the individual's family should provide, children and persons with disabilities living with their families, spouses, roommates and other individuals, still experience denials or cutbacks in service hours. Due to the ongoing lack of agreement among stakeholders regarding interpretation of federal PCA regulations, state administrative guidelines, and the best mechanisms for funding what all agree is a much-needed service, the MDDC in late 1993 authorized the use of \$20,000 for a study of these problems and questions.

To do this research, the Human Service Research Institute (HSRI) examined the Medicaid funded PCA entitlement program as it was presently operating in Massachusetts, compared it to similar programs in other states and reviewed its operations in terms of compliance with federal regulations. To monitor the study, MDDC formed a Joint PCA Committee, comprised of members of its Family Supports Steering Group and the IPI Committee. HSRI interviewed the relevant state agency directors, concerned legislators and conducted focus groups of consumers, families, service providers and advocates. Their final report advised the Council that a new PCA advocacy approach should be undertaken; in the next planning cycle MDDC will fund and help staff a collaborative working group including all parties listed above.

Meanwhile, the PCA Coalition, a group of providers and disability advocates in Massachusetts, continued to meet throughout the year

to discuss issues regarding Medicaid payments, the impact of the Internal Revenue Service regulations on PCA consumers and providers, and the situation outlined in the first paragraph of this PAS section. This Coalition was very active in working on the "Community Living" bill, which would have forced Medicaid to discontinue use of its present administrative guidelines. This bill was not passed.

In a related development, the Northeast Independent Living Center received a small DD grant to sponsor a consumer forum in September 1994 to develop a PAS advocacy platform. The participants were largely consumers, family members, advocates and service providers. Issues of concern were consumers' control, fair pay for personal care attendants, plus the impact of IRS regulations interpretation and implementation. Action on this platform will begin in 1995.

The Housing Subcommittee accomplished the following:

The numerous activities of this group and the IPI staff planner are described in "Significant Accomplishments" of the Council, in Section II.C., following. In a nutshell, members of the Housing Subcommittee and staff provided leadership to the Citizens Housing and Planning Association (CHAPA) Mixed Populations Coalition in its efforts to craft responsible housing policy and enact legislation to create protections and options for people with disabilities; worked with MHFA and EOCD to enhance resources for private housing; worked with EOHHS and DPH on task forces involving policy, legislation and budget; took positions on federal and state policy developments, proposed regulations, and legislation; and with the HOME Coalition succeeded in enacting new housing finance legislation containing \$35 million in new money from bond issuances to create new housing for elders and people with disabilities.

Transition to the new cycle: The Council throughout the 1995-97 DD State Plan cycle will continue IPI's three years of work in employment and personal assistance services. An Employment Committee began work in the fall of 1994 to continue and expand integrated employment opportunities; PCA and PAS issues have been assigned to the Individual and Family Supports Committee. Not having selected housing as a priority in the new cycle, MDHC will in 1995 reduce its activities to advocating for a suitable "Housing Opportunities" bill and overseeing the "Building Bridges" grant, awarded in 1994 to Citizens Housing and Planning Association to train persons with disabilities to advocate for themselves on housing and related budget legislative issues, and to prepare a policy book for legislators.

OBJECTIVE #3 Multi-cultural Outreach

1. Name and description of objective:
To empower people of color with disabilities by: (A) supporting and collaborating with multi-cultural communities, continuing to support constituency involvement, and promoting sensitivity to issues of cultural diversity in the Council and other human service providers; and (B) supporting the HIV/AIDS and Disability Alliance.

2. Goal:
To promote independence, productivity, and integration among all people with developmental disabilities through advocating for the maintenance and further development of individual and family supports.

3. Extent to which objective has been met:
Largely.

4. Expenditures for this objective:

A.	Federal:	\$35,000	Member Recruitment and
	Match:	<u>\$15,949</u>	Cultural Competency
		\$50,949	
B.	Federal:	\$25,000	HIV/AIDS and Disability
	Match:	<u>45,094</u>	Alliance
		\$70,094	

5. Priority area:
System Coordination and Community Education

6. Classes of activity pursued:

- Activity to increase capacities and resources of entities for improved service delivery to persons with developmental disabilities.
- Gathering information
- Outreach activity
- Training for access to or for provision of service
- State Plan development
- Activity addressing the implementation of 1990 Report findings
- Coordinating activity, other than that above
- Other advocacy activity, other than above

7. Kindly see next page for a summary of this objective's activities and accomplishments.

OBJECTIVE #3 Multi-cultural Outreach

Summary of Accomplishments

The Council's Multi-cultural Outreach Committee (MOC) had primary responsibility for this objective throughout the 1992-94 DD State Plan cycle. Throughout the cycle, MOC sponsored many HIV/AIDS and Disability Alliance activities in addition to its own committee and grantee activities. Accomplishments and outcomes include the following:

- The HIV/AIDS and Disability Alliance successfully held its third statewide conference in May, attracting approximately 75 people per day, half of whom were consumers. High consumer participation was assured through the hiring of personal care attendants, providing transportation and lodging, American Sign Language (ASL) interpretation and assistive listening devices at all workshops, and ensuring the availability of brailled, taped and large-print conference materials. A highlight held concurrently with the conference was the Directors' Dialogue, attended by 18 individuals from the HIV and disability arenas. The Dialogue focused on collaboration and compliance with the ADA, especially with regarding to requirements for reasonable accommodations for employees. The Multi-cultural AIDS Coalition, which has a reasonable accommodations policy in place, offered to share it with others. After a general discussion about the promises and pitfalls of collaboration, participants formed geographically-based teams and defined collaborative tasks they would undertake, and agreed to reconvene in six months to discuss their progress in these efforts.
- Following five years of support from the Council through MOC, the HIV/AIDS and Disability Alliance accomplished its plan to "spin off" from Council financial and staff support by the end of FFY 94. The innovative Alliance--bringing together people from a variety of backgrounds who saw the importance of working together on a common agenda--was a model to other states and national organizations. The new agency "home" for the Alliance, effective October 1994, is the Latino Health Institute of Boston.
- As the Council conducted its 1995-97 planning process, it considered how best to continue and strengthen its commitment to engaging all populations in its disability systems-change advocacy agenda. The MOC played a pivotal role in developing and advocating the adoption of a "Diversity Policy" and "Infusion Plan" for the entire DD program: their purpose is to require that cultural competence and awareness be integrated into all Council planning and activities, including those undertaken by the priority committees and all Council grantees. This required much close work by MOC leaders, staff and members, State Plan and Executive Committee members,

and AADD. The plan will be implemented in FFY 95 and thereafter. Each committee will develop its specific diversity and infusion plans, and MOC members will be encouraged to join the new "priority issue" committees to increase multi-cultural involvement as well as to help oversee the "big picture."

- In a related development, and given that a number of openings would be available in the fall for new Council members, MOC designed and the Administering Agency for Developmental Disabilities awarded two partner grants to conduct outreach to identify prospective new Council and committee members, thereby increasing multi-cultural representation on the Council and its open committees. The grantees identified several candidates for Council membership; their names were endorsed by the Council on October 1 and were forwarded to the Governor's office for consideration. Individuals identified later in the fall will be offered opportunities to join Council committees.
- Through its grants program, the Developmental Disabilities program enabled the Latino Health Institute of Boston to develop a project which conducted outreach to Latino providers, provided training to them, began outreach to 27 Latino families with a developmentally disabled family member, and formed a network of 43 Latino disability providers and consumers. The grantee has also developed several resources, including a disability training manual and "Disability Related Services for Latinos."
- Hundreds of copies of the third edition of "Disability and Diversity," an annotated bibliography of resources on disability and multi-cultural issues collected by Council staff, were disseminated around the country. The office responded to numerous requests for information or materials listed in this document.
- Staff planner Jo Bower received the first annual Service Award from the ACCESS Coalition, in recognition of her work in promoting both multi-culturalism and disability issues.

MOC members have been pleased to note a positive trend over the past year, to which the Committee's efforts and those of many others around the state have contributed: increased multi-cultural involvement in disability issues, as well as heightened attention to multi-cultural concerns by mainstream disability service providers. For example, a network of Latino providers and consumers has formed, and a network of Haitian providers has met. The Council is also supporting capacity-building in the Chinese community through a small grant. In addition, all independent living centers now have multi-cultural advisory groups, to help centers provide appropriate services to multi-cultural communities.

OBJECTIVE #4 Empowerment Through Public Policy Work

1. Description of Objective:

To promote individual and family supports for all people with developmental disabilities through policy research and analysis, advocacy, and increased public awareness.

2. Goal:

To promote the independence, productivity and integration among all people with developmental disabilities through advocating for the maintenance and further development of individual and family supports.

3. Extent to which objective has been met:

Largely (ongoing, multi-year effort).

4. Expenditure for this objective:

Federal:	\$80,000	Legislative Advocacy Training
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Match:	<u>26,667</u>	
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	\$106,667	
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Federal:	\$10,000	Behavior Modification Research
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Match:	<u>3,334</u>	Grant
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	\$13,334	
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Federal:	\$10,000	Support to Inter-Agency
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Match:	<u>3,334</u>	Coordinating Council
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	\$13,334	
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5. Priority area:

System Coordination and Community Education

6. Classes of activities that were pursued for meeting this objective:

- Activity to increase capacities and resources of entities for improved service delivery to persons with developmental disabilities
- Study or analysis
- Gathering information
- Outreach activity
- Development of model policies and procedures
- Presentation (formal or informal) to policy makers
- Training for access to or for provision of service
- Other similar activity to prevent developmental disabilities or to increase independence, productivity, and integration
- State Plan development
- Activity addressing the implementation of 1990 Report findings.
- Coordinating activity, other than above.
- Advocacy activity other than above (commenting on other State plans, State ICF/MR actions, unserved, underserved, other).

7. Kindly see next page for a summary of this objective's activities and accomplishments.

OBJECTIVE #4 Empowerment Through Public Policy Work

Summary of Accomplishments

Through the 1992-94 DD State Plan cycle, the Public Policy Committee (PPC) had primary responsibility for implementing the activities undertaken pursuant to this objective.

• NETWORKING AND LINKAGES

The Council, through both members and staff, continued to work with other advocacy organizations, coalitions and ad hoc groups to share information on disability issues and to educate policy makers on our priority issues. These included: the Massachusetts Human Services Coalition, Families Organizing For Change, Health Care For All, Massachusetts Law Reform Institute's Medicaid Defense Group, Massachusetts Health Council, Coalition for the Legal Rights of Persons with Disabilities, Disabled Persons Protection Commission, Disability Law Center, and DMR's Statewide Advisory Council. (Networking and linkages also took place through organizations and contacts referenced in Objectives 1, 2, 3, 5 and 6.)

• LEGISLATIVE PLATFORM

The Council's 1994 priority bill, An Act to Support Citizens with Disabilities and their Families, would formalize and prioritize the Commonwealth's commitment to family and individual supports, by requiring DMR and DPH, and to a lesser degree other state agencies, to plan and allocate resources for flexible, individualized options. Though the bill was reported favorably out of the legislature's Human Services & Elderly Affairs Committee, as of December 1994 it remains, likely to die, in the House Ways & Means Committee. Various efforts were made to improve provisions of the bill to increase its attractiveness to the legislature; members of Families Organizing For Change met with the chairman and his staff several times in 1994, and the bill was redrafted in August to address some of his concerns of the Chairman. The executive branch has been supportive: the Department of Mental Retardation's Commissioner actively advocated for the bill this year, and in September 1994 Charles Baker, then Secretary of the Executive Office of Health and Human Services and later the Secretary for Administration and Finance, went publicly on record in support of this bill and directed the Departments of Public Health and Mental Retardation to develop a concept paper on the implementation of this bill. DPH and DMR jointly prepared and submitted their plan to EOHHS, where it will probably be reviewed by the new secretary who begins work in January 1995. The bill will be refiled for the fourth time for the 1995 session.

The Council's 1994 legislative platform also contained six "Supported" bills:

- (1) An Act Providing Services to those Graduating from High School or Turning 22 (would make Turning 22 services an entitlement);
- (2) An Act to Establish the Division of Child, Adolescent and Family Support Services in the Department of Mental Retardation (would mandate that DMR identify and meet the special needs of children and adolescents with mental retardation and autism, and would expressly include family support services);
- (3) An Act to Provide a Home For All (would provide people with disabilities with several options for affordable housing);
- (4) An Act Relative to Services for Older Mentally Retarded Persons (would create an entitlement for services for older persons with mental retardation);
- (5) An Act to Support Community Living (would require the provisions of Personal Care Attendant (PCA) services by Medicaid to include persons living with family members or caretakers);
- (6) An Act to Protect Disabled Persons (would prohibit most extreme forms of painful or punishing aversive procedures).

All but (3), which was assigned to another committee, were reported favorably out of the Joint Human Services and Elderly Affairs Committee to the House Ways & Means Committee, where they died at the end of the 1994 legislative session. All are likely to be refiled and considered in the same or a similar form in 1995.

The Council has a special policy by which Council members and Council committees may adopt and express a position on a bill that is not on the Council's formal platform. After endorsement or opposition is approved by the Council's Public Policy Committee, an individual member or committee can work on a bill of importance to persons with disabilities, using the Council's name as having endorsed or opposed the proposed legislation. An important example of this "Support/Oppose" option in 1994 was the IPI Committee's request that the Council endorse "An Act to Improve Housing Opportunities for Elders and Persons with Disabilities." The IPI Committee and staff working with a mixed population housing coalition helped produce this bill which contained several important provisions for people with disabilities. Despite a promising start and support from the Governor, the House in mid-December enacted an unsatisfactory substitute. By the end of the 1994 session disability advocates concluded that they could not support the House version. For more information, see Objective #2, above.

By contrast, another bill on the "Support" list, "An Act Establishing Alternative Procedures for Determining Competency to Testify and for Taking Testimony of a Witness with Mental Retardation," was signed into law on January 3, 1994. The Council's staff director had been invited in 1992 to work with a broad-based task force committed to promoting the right of persons with mental retardation who have been victims of crimes or witnesses to them, to increased access to and supports from the Massachusetts courts. The task force, composed of citizen and professional advocates, attorneys, DMR, and representatives of the

state attorney general and the Middlesex County district attorney, first prepared a report detailing the problems of access and accommodation for citizens with retardation, then wrote and promoted the bill which specifies mechanisms for courts to employ, in line with the Americans with Disabilities Act. The Council had contributed significantly to the research and writing of the report, which was widely disseminated. The legislative champion was Representative Carol Donovan, who was honored for her work at our March legislative reception.

● LEGISLATIVE RECEPTION

Secretary Charles Baker of the Executive Office of Health and Human Services conveyed greetings from the Governor at the Council's highly successful sixteenth annual Legislative Reception in March at the State House in Boston. "Legislators of the Year" awards, paintings created by two individuals with developmental disabilities, were presented to Senator Michael J. Barrett, and Representative Carolyn Donovan by the artists Bohill Wong and John Colby. Jessica Vohs, a consumer, and Genevieve Potter, a parent, addressed the audience of more than 250 legislators, consumers and advocates from state and private agencies. As in prior years, Arc Massachusetts co-hosted, and sixty-two other agencies co-sponsored the reception. Our theme, "Do The Right Thing: Support Families and Community Services," focused on how some individuals and families urgently need funding for the individualized supports needed to live independently in their communities, while others have benefitted from them. During the Reception the Council and The Arc presented our respective legislative and budget agendas to the legislature. After the Reception the Council's legislative advocacy training grantee paired groups of attendees with team leaders, who brought them around the State House to visit with their own legislators to communicate to them the importance of services for persons with disabilities and their families.

● LEGISLATIVE TRAINING

The third year of our Legislative Advocacy Training Grant involved several tiers of training. Twelve basic legislative advocacy training sessions were conducted statewide for consumers and advocates, including training targeted to multicultural communities including Latino, Native American, African American, Vietnamese, Cambodian and Russian; Families Organizing For Change regional groups (five), and rural areas including the Islands and northwestern Massachusetts. Advanced training sessions at the State House in Boston focused on budget advocacy and organizing legislative campaigns. A new Train-the-Trainer program targeted advocacy groups based on geographic distribution and disability diversity with special focus on low incidence groups. A three-day session was presented to individuals from twelve organizations who then were able to return to their organizations and offer legislative advocacy training to their members. The grantee used the occasion of legislative committee hearings on bills in March to

conduct a training on how to testify on a bill at a hearing. In addition, as noted above, the grantee conducted team-led visits to legislators and gave a tour of the State House to first-time participants at the Legislative Reception.

- "DO THE RIGHT THING" CAMPAIGN

Individuals with disabilities, family members, workers and providers of community services joined in this campaign, now in its second year, to ask the Legislature to "do the right thing," i.e. provide adequate funding to pay direct care workers and increase resources within (for more client access to) the community services system. People with mental retardation who have remained at home with their families have not received their fair share of DMR-funded services. The demand has reached a crisis level as older parents become unable to care for their sons and daughters. Over 3,000 adults with mental retardation are without essential residential or day services. Nearly 900 of these have family caregivers over the age of 60. Only 1/4 of those students completing special education programs receive the services for which they qualify as young adults. Contracts to community-based service providers have been level-funded for six years, resulting in a 23% reduction in buying power.

Through the expansion of DMR's Home and Community-Based Medicaid Waiver, Massachusetts should be able to receive up to \$177 million in new Medicaid funds over the next five years. The Arc Massachusetts inaugurated the "Do The Right Thing Campaign" to publicize the opportunity provided by this infusion of new federal dollars to upgrade existing programs and expand services for those without them; it proposed that \$45 million could be "retained" by DMR (rather than going into the Commonwealth's General Fund) and allocated to waiting list clients and direct care staff. The Council endorsed this campaign. Advocates had requested increased funding in the FY95 state budget for Older Unserved (\$5 million), Respite Care (\$20.2), Turning 22 (\$3 million), and for direct care staff salaries (\$15 million). Some new monies were appropriated but not for direct care staff salaries. Throughout the summer and fall of 1994 advocates sought a supplemental budget of \$10 million for salaries but none was passed. Meanwhile DMR at the end of December 1994, halfway through state fiscal 1995, faces a shortfall of \$9.8 million just to maintain its present level of services; it will seek a supplemental budget to avoid having to make cuts.

- BEHAVIOR MODIFICATION RESEARCH PROJECT

The Disability Law Center (DLC), working on a \$10,000 grant to examine the behavior modification regulations, guidelines, and policies of all state agencies, compiled and summarized all applicable state behavior management laws and regulations, comparing and contrasting them to identify areas of uniformity and conflict, with the goal of recommending strategies for improving the uniformity of the state agencies standards and the

accountability of their conduct in this sensitive area. In 1995, the Council's Legislative Committee, successor to the Public Policy Committee, will examine DLC's draft report and recommendations, currently under revision by them, to determine whether and how we can promote a single state policy for the use of behavior modification treatment techniques.

• STATE BUDGET ADVOCACY

Although Massachusetts has climbed out of its severe fiscal crisis, much of this recovery has been financed by eliminating the safety net under many vulnerable citizens. Despite strenuous advocacy for continued funding for services for individuals with disabilities and their families, cuts continued to slice away needed services. According to Judy Meredith, dean of State House social welfare lobbyists, "The community-based human services system is underfunded and undercapitalized, the whole infrastructure of social services is weak and fragile, cash benefits are barely enough to keep people alive and in fact drive people into homelessness." (Boston Globe, Oct. 15, 1994, p. 21) Despite much discussion and debate about "welfare reform," the legislative and executive branches could not all agree so no formal action was taken during the 1994 session.

Much of the Council's legislative activity involved the FY1995 state budget. At four points throughout the fiscal year, the Council submitted budget testimony: to the Executive Office of Health & Human Services, both the House and Senate Ways & Means Committees, and the Joint Conference Committee on the State FY 1995 Budget, articulating the needs of persons with disabilities and their families, and warning about the effect the reductions in services would have on them. Key points have included:

* CommonHealth, a program for working adults with disabilities and families with a child with a disability, was cut by \$654,000. or 123 slots. There was no provision to grandfather people who might be cut off. Many people with disabilities who cannot meet the 40 hour a month work requirement will be without the health care they need.

* At the Mass. Rehabilitation Commission only the Statewide Head Injury Program received an increase, however services for the severely head injured are so expensive that only a few new people will be served with the additional \$200,000. Funding for the computerized accessible Housing Registry was left out and has been added to the housing bill mentioned under "legislation" above. Independent living services were level-funded, which means drastically underfunded independent living centers and protective services will not be able to meet the needs of people with disabilities in the community.

* The Governor's Commission on Mental Retardation is level-funded so its budget is insufficient to meet its expanded responsibilities. The Disabled Persons Protection Commission is

level-funded although the numbers of reports of alleged abuse rising steeply by about a third every year; despite this, DPPC experienced a 7% cut in FY94.

* Proposed budget language that Medicaid PCA services should be provided even where there are members of the household present was not passed, thus the policy to deny eligibility for PCA services will continue to place tremendous burdens on family and friends. The Mass. Commission for the Blind's Turning 22 program serving severely disabled deaf/blind people aging out of special education programs was underfunded so five eligible persons will not be served. The special DD Dental Health Program at the Department of Public Health was cut by another \$18,000, continuing a series of cuts over the last four years.

* At the Department of Mental Retardation, transportation was cut by \$450,000. On the plus side, respite received an additional \$1.3 million, Older Unserved an extra \$4 million, Turning 22 an additional \$4.4 million. However the \$10 million suggested for the worst-paid of human services workers in vendor companies, most of whom have gone without raises for six years, was eliminated.

Other matters involving legislation and public policy are discussed in the narratives describing other Council objectives, and in Section V., below.

OBJECTIVE #5 The DD "Family"

1. Name and description of objective:

To participate actively as a member council in the National Association of Developmental Disabilities Councils, Inc. (NADDC); to work jointly with the Disability Law Center (P&A) and the Institute for Community Inclusion at Children's Hospital and the Shriver Center (UAPs); and to maintain active liaison with regional and national offices of the federal Administration on Developmental Disabilities (ADD).

2. Goal:

To promote independence, productivity, and integration among all people with developmental disabilities through advocating for the maintenance and further development of individual and family supports.

3. Extent to which objective has been met:

Largely.

4. Expenditures for this objective:

\$8,963 (NADDC)

5. Priority area:

System Coordination & Community Education

6. Classes of activities that were pursued for meeting the objective:

- Activity to increase capacities and resources of entities for improved service delivery to persons with developmental disabilities
- Study or analysis
- Gathering information
- Outreach activity
- Presentation (formal or informal to policy makers)
- Other similar activity to prevent developmental disabilities or to increase independence, productivity and integration
- Activity addressing the implementation of 1990 Report findings

7. Kindly see next page for a summary of this objective's activities and accomplishments.

OBJECTIVE #5

The DD "Family"

Summary of Accomplishments

A) THE COUNCIL CONTINUED ITS STRONG MEMBER AND STAFF SUPPORT TO THE NATIONAL ASSOCIATION OF DEVELOPMENTAL DISABILITIES COUNCILS' WORK TO PROMOTE THE DD POLICY AGENDA IN THE NATIONAL ARENA AND TO SUPPORT DD COUNCILS AROUND THE COUNTRY:

- MDDC's three official delegates to the national association continue to be the chairperson, consumer representative, and executive director. Howard Wayne, who began service as the new chairperson in November 1993, became active by attending all three NADDC meetings and joining its Finance Committees.

Two unexpected challenges confronted NADDC this past year: the Massachusetts delegation devoted considerable time and energy to the satisfactory resolution of both.

(1) The President's budget request submitted to the Congress in January 1994 contained an unexpected reduction of \$10 million in funding to DD Councils. This surprise stimulated months of strategizing and communications, to ensure that the final level of federal appropriations to councils, finalized in the fall of 1994, did not include any cuts. In November 1994 we learned that Massachusetts will receive some \$25K more next year!

(2) A number of large Councils unexpectedly withdrew from NADDC, leaving a fiscal problem and a crisis of confidence. With many others, the Massachusetts delegates worked diligently to assist the association and its newly-elected volunteer leadership through a self-assessment and other transition activities throughout calendar 1994. The result by the end of the year was a restructured organization and a reinvigorated membership of committed Councils.

- Consumer representative Barbara Gopen began the year as vice-chair of NADDC's Council Services Committee, and active on the that committee's conference planning subcommittee. She served also as the alternate representative from New England to NADDC's board of directors (in which capacity she convened and chaired regional meetings at two national meetings), until she was elected Secretary of the Association in the spring!

- Executive director Jody Williams remained active on the NADDC's Public Policy Committee & the Children's Issues Committee, as well as the Executive Director's caucus. Throughout 1993, she contributed significantly to the Association's work on the draft versions of the reauthorization of the DD Act, serving on three NADDC task forces addressing the findings & purposes, the state plan, and whether the Act's scope should be expanded to all disabilities; she worked in early 1994 to promote Congressional attention, which had been delayed, to reauthorization of the Act, which was signed in April 1994.

B) THE COUNCIL CONTINUED STRONG MEMBER AND STAFF SUPPORT TO THE THREE OTHER MEMBERS OF THE DD "FAMILY" IN MASSACHUSETTS:

- Several members and staff continued to advise both UAPs through various Advisory Councils, assisting them in planning new projects and accessing new resources, including multi-cultural contacts. An important development was the expansion of one Massachusetts "university affiliated program" in January: the program at Children's Hospital changed its name and expanded its mission when it became the Institute for Community Inclusion in January 1994; we provided input to the peer review conducted the same month. An example of four-way collaboration was joint co-sponsorship of a well-received national teleconference on "Barrier-Free Environments for People who are Aging and Developmentally Disabled," on May 26, 1994.

- The Council's executive director, who has served on the Disability Law Center's (DLC) board of directors since September 1992, assisted this "DD protection and advocacy" organization to recruit new members, to maintain state legal services funding in the face of threatened serious cuts, to successfully undergo a program audit from a state funding course, and to design and implement a first-ever system for evaluation of the staff director. The previous year, DLC had reorganized internally to add a DD unit, and several members of the board now represent DD constituencies.

C) THE COUNCIL MAINTAINED CLOSE LIAISON WITH FEDERAL ADMINISTRATION ON DEVELOPMENTAL DISABILITIES (ADD), AT NATIONAL AND REGIONAL LEVELS:

- We welcomed new ADD Commissioner Robert Williams to New England via his first commissioner teleconference in December 1993; and later assisted with arrangements for him to address DD program representatives while in Boston on June 1.

- Council leaders and staff took part in several New England regional meetings convened by federal DD program specialist and/or NADDC regional representatives. Staff formally conveyed New England councils' collective decision that--despite our interest--we were not in position to apply as a group for a DD national significance grant examining whether councils should expand their focus from the federally-defined "DD" population to some more broadly-defined population of persons with disabilities.

- The Council and AADD implemented the requirements and recommendations from ADD's Program Administrative Review (PAR), conducted in September 1993, by increasing Council member involvement in the preparation and oversight of the DD program budget and in various grantee activities. Preparation of the proposed FFY1995 program budget was especially challenging, as we were on a roller coaster until after the new federal fiscal year began, uncertain as to the amount of the 1995 appropriation.

OBJECTIVE #6 Support Innovative Grassroots Activities

1. Name and description of objective:

Continue to fund efforts to improve the monitoring and evaluation of DD grants; continue to provide small grants to community based organizations offering creative approaches to maximizing independence, productivity and integration; develop a new administrative grant process to respond to time-sensitive community funding needs.

2. Goal:

To promote independence, productivity and integration among all people with developmental disabilities through advocating for the maintenance and further development of individual and family supports.

3. Extent to which objective has been met:

The initial evaluation of the DD Grants Program has been completed. The grantee will submit recommendations for improving the monitoring and evaluation of grants in January 1995. The 1994 Small and Small Support Grant Programs continue to elicit the highest number of requests for funding of all DD funded grant programs.

4. Expenditures for this objective:

A. Federal	\$50,000	Monitoring & Evaluation*
Match	\$16,667	
	\$66,667	
B. Federal	\$75,000	Small & Small Support*
Match	\$25,000	
	\$100,000	
C. Federal	\$ 6,400	Administrative
Match	\$ 1,333	
	\$ 7,733	

*Projections, actual awards will be made early in FFY 1995.

5. Priority area:

Systems Coordination and Community Education; Employment.

6. Classes of activities pursued:

- Activity to increase capacities and resources of entities for improved service delivery
- Study or analysis
- Gathering information
- Other similar activities to prevent Developmental Disabilities or to increase independence, productivity and integration
- Coordinating activity, other than above

7. Kindly see next page for summary of this objective's activities and accomplishments.

OBJECTIVE #6 SUPPORT INNOVATIVE GRASSROOTS ACTIVITIES

Summary of Accomplishments

This objective was implemented by the Administering Agency for Developmental Disabilities (AADD), the "Designated State Agency" for the MDDC, in cooperation with the Council's Grants Policy Administration Committee (GPAC). The AADD also maintains responsibility for the award, monitoring and evaluation of DD Program grants.

A grant was awarded in January 1994 to conduct a thorough review and analysis of the application, award, monitoring and evaluation components of the DD grants program. The overall goal of the project is to provide specific recommendations for improving the effectiveness of DD grants, in terms of both the impact on individuals with developmental disabilities, and the effectiveness in furthering MDDC State Plan objectives. The grantee conducted a review of State Plan and grant related documents, interviewed members, MDDC and AADD staff, Federal and State officials, consumers, and representatives from non-profit organizations, and researched best practices in effective grant management. The final report is due in January 1995. GPAC will review the project results and work with the AADD to implement additional improvements in the grants program.

FFY 94 is the fifth consecutive year in which the Massachusetts DD Program offered funding under the Small Grants Program (\$5,000 to \$10,000 awards), and the third year of the Small Supports Grants Program (\$2,000 or less). Although the objective for these grants is set forth in the State Plan as "subject to the availability of funds," the Council was again able to fully fund the objective. This was achieved through administrative and operating cost savings, and by moving unexpended funds from administrative grants objective into the Small and Small Support Grant programs.

Under these programs, applicant agencies are provided the opportunity to propose innovative projects which maximize the use of DD program funds to improve the quality of life of individuals with developmental disabilities and their families. In FFY 1994, the AADD again received over 200 requests for applications. Awards will be made in January 1995.

In order to respond to time-sensitive community funding needs, a flexible new administrative grants process was implemented which allowed the Council to award small amounts of money on an as-requested basis. In an effort to avoid being overwhelmed with funding requests, GPAC developed strict award criteria, and as a result, the number of requests for funding was fewer than projected. GPAC will revisit this issue in the coming fiscal year.

Nineteen "Small" and "Small Support" Grant Projects funded with FFY 93 dollars were implemented during FFY 94. The success of this program is evident in the wide range of innovative activities that

were implemented by the grantees.

The following projects were implemented during FFY 94 with funds awarded from the FFY 93 Small Grants Program:

Association for Community Living, Springfield, MA - \$10,000 to conduct a statewide conference for people with developmental disabilities, family and other community members on the Family Support movement, and to provide follow up support to families.

Community Connections, Yarmouthport, MA - \$5,000 to develop a consumer resource guide to services for Cape Cod and the Islands.

D.E.A.F., Inc., Allston, MA - \$10,000 to support planning activities for the first National Hispanic Council of the Deaf and Hard of Hearing Conference in Boston, November 16 - 19, 1994.

Horace Mann Education Associates, Franklin, MA - \$10,000 to conduct education and training to nursing and paraprofessional staff on treating individuals with developmental disabilities in emergency room settings.

Northeast Independent Living Program, Lawrence, MA - \$10,000 to organize a statewide summit to train and empower persons with developmental disabilities and their families to improve personal assistance services in Massachusetts.

South Cove Community Health Center, Boston, MA - \$10,024 to develop and disseminate a resource directory and related materials in Chinese, and to provide disability awareness workshops to consumers and families of the Chinese community in Greater Boston.

The following projects were implemented during FFY 94 with funds awarded from the FFY 93 Supports Grants Program:

Acton-Boxborough Regional School District, Acton, MA - \$2,000 toward the development of an audio-visual media library for individuals with developmental disabilities.

Bay Cove Human Services, Boston, MA - \$1,100 to hire an individual with developmental disabilities to provide community education and promote inclusion to organizations and high schools in the Boston area.

Cambodian Community of Massachusetts, Chelsea, MA - \$2,000 to implement a culturally and linguistically appropriate survey to determine the prevalence of developmental disabilities in the adult Cambodian community.

Cape Organization for the Rights of the Disabled, Hyannis, MA - \$2,000 to develop and disseminate information on how the Americans

with Disabilities Act applies to public schools above and beyond Chapter 766.

Center for Humanistic Change, Springfield, MA - \$\$1,937 to research and disseminate information about educational opportunities in Berkshire County for adults with developmental disabilities.

Disabled Persons Protection Commission, Boston, MA - \$1,848 to reproduce copies of the DPPC brochure, statute summary and seven page statute in Braille and large print, and to record these items on audio cassettes.

Information Ctr. for Individuals with Disabilities, Boston, MA - \$2,000 to convert, prepare and enter disability related resource data into their newly acquired Textbase computer system.

Martin Luther King, Jr. Community Center, Springfield, MA - \$2,000 to produce a comprehensive Spanish/English service directory for African American and Hispanic individuals with developmental disabilities and their families in Springfield.

Outdoor Explorations/The Tides Foundation, Cambridge, MA - \$2,000 to conduct outreach to consumers from non-dominant cultures to include them in volunteer community service projects.

Road to Responsibility, Marshfield, MA - \$2,000 to hire an individual with developmental disabilities to give presentations to school children to educate them about disabilities, and to work with other consumers to do the same.

The SHARE Foundation, UMass Dartmouth, North Dartmouth, MA - \$1,903 toward developing a software package and providing training which will enable consumers using single switch computers to access electronic information networks.

Seaside Education Associates/DMR, Boston, MA - \$2,000 to increase the involvement of individuals with developmental disabilities in DMR's quality enhancement activities.

Vineyard Employment Options, Vineyard Haven, MA - \$2,000 to conduct a seminar for area business and community leaders to expand supported employment opportunities for individuals with developmental disabilities.

OBJECTIVE #7**Volunteer Development****1. Name and description of objective:**

To promote the development of volunteer Council and committee members as effective advocates and leaders, by continuing to identify and support their participation and leadership in all Council activities.

2. Goal:

To promote independence, productivity and integration among all people with developmental disabilities through advocating for the maintenance and further development of individual and family supports.

3. Extent to which objective has been met:

Largely.

4. Expenditures for this objective:

No grants were made under this objective.

5. Priority area:

System Coordination and Community Education.

6. Classes of activities that were pursued for meeting the objective:

- Activity to increase capacities and resources of entities for improved service delivery to persons with developmental disabilities.
- Training for access to or for provision of service.
- State Plan development.

7. Kindly see next page for a summary of this objective's activities and accomplishments.

OBJECTIVE #7 Volunteer Development

Summary of Accomplishments

A full agenda of activities to encourage effective volunteer participation and leadership was planned by and for the Council for FFY 1994, the third year of the 1992-1994 plan cycle. A change in leadership took place early in the new year: vice-chair Barbara Gopen presided over the Council for several months as interim chair, following Dr. Gerald Healy's resignation which became effective in September 1993. In early November Governor Weld and Lt. Governor Celluci announced the appointment of Mr. Howard J. Wayne, a Boston attorney, as the new chairperson. Early in the course of the year two other new members were also appointed to fill vacancies; later a cherished longstanding member, Vivienne Thomson, died in June.

Proposals regarding new members: Early in calendar 1994 Mr. Wayne named a "1994 Member Recommendations" Committee, to conduct outreach and prepare recommendations to the council for reappointments and new appointments to forward to the Governor for his action in the fall of 1994, given that nearly every member's term would expire in October of the year. The committee examined two dozen applications from "new" individuals interested in an appointment, and surveyed all present members who were eligible for reappointment. In a related development, Mr. Wayne and the Governor's office decided to add representatives of the Dept. of Mental Retardation and the office of the Attorney General, and three other state agencies communicated that their representative will be changing. Invitations have been issued also to the state House of Representatives and the Senate, to designate individuals to serve on the Council.

The Council on October 1, 1994, ratified the Member Committee's recommendations, which include primary consumers and persons from diverse cultural backgrounds, and forwarded them to the Governor's office.

The Program Committee, which had been reconvened in early 1992, cooperated with the 1995-95 State Plan committee to design and conduct meetings. (See the following, Objective #8, regarding new State Plan activities.)

Council meetings and events: The October 1993 meeting initiated the discussion of goals and objectives for the 1995-97 State Plan. To give us a national perspective, we invited Denise Rozell from the National Association of Developmental Disabilities Councils (NADDC) to comment on the national advocacy perspective on key issues impacting persons with developmental disabilities, after which we conducted small discussion groups so that Council members as well as standing committee members (who need not be Council members) could contribute to the process of establishing the upcoming plan cycle's goals and objectives. At a brief mid-

December meeting the new chairperson was introduced to his fellow Council members and representatives of the other Massachusetts DD programs. We appreciated the excellent publicity given the Council and its work in the February 1994 newsletter of the Information Center for Individuals with Disabilities.

The winter 1994 meeting, postponed after a February snowstorm, featured selection of the Legislative Platform plus political and issue updates from our legislative training grantee and New England's federal DD program official. Later in March the Council co-sponsored the 16th Annual Developmental Disabilities and Mental Retardation Legislative Reception, probably the best ever: as has become our tradition, two legislators who were very active and supportive of people with disabilities were honored. (See narrative above on Objective #4 for more details.) In April we co-sponsored and publicized an exciting Boston rally in favor of national health care. The May Council meeting featured a guided decision-making process for the Council's selecting major issue priorities, and afforded the public an opportunity for oral comment and participation in Council deliberations.

In June we were privileged to host, with 30 other agencies co-sponsoring, an address by disability public policy and national health reform expert Allan Bergman of UCPA in Washington, on universal health care and disabilities. In the spring and early summer, the Executive Committee met several times, finalizing the State Plan, learning about the budget and considering initial versions of the 1995 version, and adopting on behalf of the Council a new multi-cultural diversity policy and plan for "infusing" out multi-cultural talents and concerns throughout the upcoming cycle's work.

On October 1 the Council heard from three experts on managed health care systems; the panelists were our former chairperson and practicing surgeon and hospital administrator Dr. Gerald Healy, a representative from our state's Medicaid agency, which has instituted a variety of managed care options, and a parent-consumer advocate. This meeting initiated the Council's education on health matters, a new priority for 1995 and succeeding years.

Member participation and empowerment: In other volunteer development activities, Council members continue to be encouraged to attend training and conferences, to seek appointments to state advisory bodies, to be more informed and active in communications with the legislature, and to become involved individually and in conjunction with the Council and other organizations, in ways that both empower them and advance the Council's overall objectives. For example, in 1994, we:

- presented budget information to members at Executive and Council meetings, and formalized a process for member involvement in the preparation, adoption, and oversight of the DD program budget via a Finance Committee convened by the Council chair;

- adopted a revised committee structure, to track the four major objectives in the new 1995-97 State Plan, to begin functioning in the fall-early winter of 1994. We continued successful cross-committee participation in the design of two new grant projects (begun the previous year), and following directions from the Grants Policy Administration Committee significantly increased options for member involvement with grant projects, either as members of the project advisory committee, or as specially-assigned liaisons from the council committee to the individual grant project or a cluster of related projects.
- strengthened our commitment to multi-culturalism by adopting a strong "Diversity Policy" and companion "Infusion Plan," whereby the activities of all committees, grantees and the full Council are to become better integrated with cultural competency and sensitivity to people with disabilities from various cultures and backgrounds. Concomitantly, two outreach grants were awarded to seek out individuals who would be interested in Council membership or service on a committee.
- ensured proper composition and functioning of the Council, through recommendations to the Governor about new members, as described above;
- continued to sponsor individual Council members and/or other consumers' attendance at appropriate conferences;
- updated the member handbook and the office and public policy manuals for member and staff reference;
- provided training and educational opportunities for members, via educational Council and Council-sponsored meetings described above, in addition to social interchange and networking at Council functions; we improved forms to evaluate members' satisfaction with the meetings;
- continued to serve as a resource and information center for the members, adding a new listing of "Events, Resources, and Volunteer Opportunities," while modestly reducing the number and volume of mailings.
- proudly "lost" one of our members, Speed Davis, on the DD Council as director of the Mass. Office on Disability, to his new post in Washington, where he serves now as the executive director of the National Council on Disability.

OBJECTIVE # 8 Implementation of State Plan

1. Name and description of objective:

To implement activities in 1994 in the selected federal priority areas of "employment" and "system coordination and community education," via Council member, committee, grantee, and staff work as specified in the above seven 1994 State Plan Objectives.

2. Goal:

To promote independence, productivity, and integration among all people with developmental disabilities through advocating for the maintenance and further development of individual and family supports.

3. Extent to which objective has been met:

Largely.

4. Expenditures for this objective:

Federal	\$363,239	(In addition, kindly see
Match	\$121,080	amounts for grants in
		Objectives 1-7.)

5. Priority area:

All federal priority areas were in some way addressed in this objective, which refers to the preparation, oversight, coordination, and implementation of the entire 1992-94 State Plan.

6. Classes of activities that were pursued for meeting the objective:

- Activity to increase capacities and resources of entities for improved services delivery to persons with developmental disabilities
- Study or analysis
- Gathering information
- Demonstration project
- Outreach activity
- Development of model policies and procedures
- Presentation (formal or informal to policy makers)
- Training for access to or for provision of service
- Other similar activity to prevent developmental disabilities or to increase independence, productivity and integration
- State Plan development
- Activity addressing the implementation of 1990 Report findings
- Coordinating activity, other than above
- Advocacy activity other than above (commenting on other State Plans, ICF/MR actions, unserved/underserved, other)

7. Kindly see next page for a summary of this objective's activities and accomplishments.

Summary of Accomplishments

The annual DD state plan is the vehicle by which the volunteer (citizen and consumer directed) DD Council communicates its mission to the public, and in which we specify our objectives for the coming year. These objectives state our intentions, and specify our plans for the use of our human and fiscal resources to further responsible systems change generated by the empowerment and contributions of persons with disabilities, and their families and friends.

This objective refers to the coordination and implementation of the 1994 DD state plan, as well as to the planning, research, outreach and writing of the new 1995-1997 State Plan.

1994 was the third year and final year of the 1992-94 DD State Plan. Major accomplishments for 1994 have been outlined in the narratives accompanying the preceding seven objectives, with some highlights as well in Sections II.B and II.C, following. The planning for the new 1995-97 cycle is summarized below.

Unexpected features of the year: The year was not a routine one for several reasons: (1) the change in Council leadership, involving three persons between August and November 1993; (2) the simultaneous winding-down of the "old" 1992-94 plan and the gearing-up of the "new" 1995-97 one, the latter a challenging and consuming task for both members and staff; (3) the unexpected challenge presented by the January 1994 news that Councils might lose \$10 million in funding; this was tempered early by the good news that the state would contribute a \$50,000 match to our federal funds (the first in many years) and much later with the news that Congress finally increased the overall DD appropriations); (4) professional staff shortages throughout much of the year due to accidents and illnesses followed by the departure of two staff in the fall of 1994, while the new Personnel Committee suggested consideration of different staff "deployment" options; 5) our disappointment due to the last-minute cancellation, for reasons beyond the Council's control, of our long-hoped-for office move into more spacious and ADA-compliant quarters.

The 1992-94 three-year state plan was approved by the federal government in August 1991, the 1993 update in September 1992, and the 1994 update in September 1993. Entitled Putting the Pieces Together, all three years' versions of the plan contain narratives analyzing developments in Massachusetts and explaining the Council's values and views, in addition to the seven specific objectives for the year's work. Seven hundred fifty copies of the 1994 plan were distributed in November-December, and several hundred additional copies following a second printing. Charts summarizing key public agency programs and services and interagency initiatives were placed on computer in 1994; kept current by staff,

these are available in the complete version of the 1995 Plan.

As during the two preceding years, the Council's four issue-focused committees continued to carry out the lion's share of our systems change advocacy (see Objective #s 1-4) throughout FFY 1994, while cementing a close working relationship with the Grants Policy Administration Committee (GPAC), the fifth standing committee of the Council. The small grants program grew in popularity (see #5), while two Council committees (FSSG and IPI) worked actively on joint projects and/or used "public outreach" dollars to unite with other groups to sponsor spontaneous projects and activities. The Multi-cultural Outreach Committee inspired the Council to adopt a new "Diversity Policy" and "Infusion Plan" to guide our work in the new cycle.

The Council continued to nurture close relations with others in our "DD family" in the state, region and nation (see #6); and the Executive Committee played a key role both in setting policy and direction, as well as facilitating linkages and communication within the Council and with outside organizations (see #s 4, 7 and 8, below). Interested persons continued to be actively involved in the four committees responsible for Objectives 1-4 continued to be open to interested members of the public, thereby increasing the resources available within the Council's DD advocacy circles.

Changes recommended in three reports: Not highlighted in the 1994 plan but important in the year's work were the commitments of the Council's vice-chair and new chair, and the Council and AADD staff directors, to achieving certain changes (i.e. more member involvement in budget and grants matters) required by the federal Program Administrative Review (PAR) conducted in September 1993, in addition to other changes in certain office procedures and Council and staff communications recommended by a state Dept. of Personnel Administration program/agency audit concluded a few months earlier. We believe that as of the close of calendar 1994 we have carried out the PAR requirements and the key DPA recommendations. A third report initiated by an Executive Office for Administration and Finance consultant urged "co-location" of the DD program with the Mass Office on Disability and the agency charged with oversight of the Commonwealth's compliance with the mental retardation consent decrees. While this idea was excellent in theory it turned out after much consultation, research and analysis that there was no space suitable to jointly house even two of the three programs.

Developments with Other Statewide Disability Advocacy Groups: Initial operations of two important new bodies, welcomed by the Council and other disability advocates, commenced in 1993-1994. The new Governor's Commission on Mental Retardation opened its doors in the fall of 1993; likewise the Governor's Interagency Disability Services Coordinating Council, consisting of 15 state agencies running disability services or advocacy programs convened

by the Mass. Office on Disability and actively supported by the DD program, commenced its work. Unfortunately, no appointments have yet been made to Coordinating Council's sister agency, the Disability Consumer Advisory Council, despite considerable volunteer and MOD staff time being put into reviewing some 200 applications from persons with disabilities interested in serving.

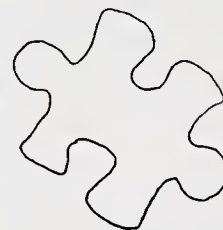
Preparing the 1995-97 State Plan: A special State Plan Committee, appointed in June 1993, met 15 times to oversee the Council's preparation of the new plan. Its focus was to create then oversee a thorough planning process involving members, committees, interested agencies, and the general public; staff then worked on particulars of selected objectives and finalized the objectives and other information to meet the federal requirements. The committee worked from January to May to develop and circulate several versions of questionnaires for the purpose of obtaining public input on desired priorities; it hosted Council meetings and directed the standing committees to devote open meetings to consider various issues and approaches; it sought to guide members as to how to continue much of what we had been working on, incorporate some new concerns while not over-burdening the Council by trying to do everything all at once. The Council in May selected three major issue priorities--two "old" (Employment and Supports) and one "new" (Health), and organizationally recommitted itself to cross-cutting work on legislation, grants, and multi-cultural competency. The body reluctantly decided--because of and the importance of focusing limited resources and energies in order to be effective--NOT to prioritize a number of vital issues including education, housing, and transportation.

The initial version of the 1995-97 document, entitled Righting the Scales for Persons with Disabilities and Their Families, was submitted to the federal government in mid-August 1994, then printed and distributed to Council members. Following the addition of specific information regarding intended activities and expected costs requested by federal officials, the plan was accepted conditional upon our complying with two new statutory requirements: a new conflict of interest policy, and proof of additional "post-plan" outreach to solicit additional public comment on the almost-final plan. The plan was then prepared in two summary versions as well as the changed full version, and hundreds of copies were distributed; in addition, a brief brochure mailed to numerous agencies advised about how to obtain the plan and how to make comments by January 15, 1995. As of this writing (in late December 1994) several written and many oral comments have indicated agreement with the priorities and have recommended some specific new ideas for pursuing them.

The State Plan Committee, in close liaison with the Executive Committee, discussed and developed a committee structure suitable to carry out the new plan: there will be three open-to-the-public

"priority issue" committees, and three Council-member-only "administrative" committees. The structure will be re-examined in the middle of FFY 1995.

PUTTING THE PIECES TOGETHER:



CREATING COMMUNITY SUPPORTS FOR INDIVIDUALS AND
FAMILIES

MASSACHUSETTS DEVELOPMENTAL DISABILITIES STATE PLAN

FEDERAL FISCAL YEARS 1992 - 1994

From cycle to cycle: We hope you will conclude after reading this report that the Massachusetts DD program--the Council and the Administering Agency--has substantially succeeded in meeting its eight ambitious objectives set forth in the 1992-94 DD State Plan. In those instances where certain grant projects and late-started Council activities could not have been completed by the end of 1994, one or more of the Council committees has been assigned follow-up responsibility to ensure their successful completion and connection to activities conducted under the new plan.

LIVES IN THE BALANCE:

RIGHTING the SCALES

For PERSONS with DISABILITIES
And THEIR FAMILIES



MASSACHUSETTS DEVELOPMENTAL DISABILITIES STATE PLAN

FEDERAL FISCAL YEARS 1995 - 1997

We thank the many talented and energetic people who have contributed in so many ways to our work during the past three years!

II. B. INNOVATIVE ACTIVITIES IN 1994

It is difficult each year to select those Council or Council-sponsored activities that were particularly innovative. A few are highlighted below.

• SENSITIVITY TRAINING FOR MEDICAL/HEALTH CARE PROVIDERS

The three small grant projects described below educated health care providers on how to better work with people with developmental disabilities. Individually and collectively they illustrate how innovations originating outside the Council have been supported by the Council's and AADD's small grants program.

(1) The Greater Boston Association for Retarded Citizens (GBARC) implemented a sensitivity training project with third year medical students from Boston University School of Medicine. "Operation House Call" integrates a two-hour interactive lecture into the pediatric rotation of every third year medical student (of which there are 150/year), followed by a two-hour home visit with the family of a child with a disability. Parents function as teachers to break down barriers and provide real life experiences for the students. The student thus sees how a child's disability affects a family in its day-to-day life, and how the family's interaction with the medical community shapes family attitudes.

The Family Support Steering Group used some "Public Awareness" funds for Phase II of Operation House Call, to market the project through presentations at four key national conventions and through outreach to three additional medical schools in Massachusetts.

(2) The University of Massachusetts Medical School developed another approach to expose second year medical students to people with developmental disabilities in a low-anxiety supportive environment: A Developmentally Disabled Standardized Patient Program to Teach and Evaluate Clinical Skills.

Standardized Patients (SPs) are lay people who have been trained to replicate a clinical encounter in a consistent and realistic fashion, to evaluate and teach clinical skills to medical students. This project trained people with developmental disabilities to work as standardized patients (DDSPs), targeting people with vision or hearing impairments, people who use braces and crutches, and people who have major neurological deficits such as spinal cord lesions or cerebral palsy. The three other medical schools which have worked with the University of Mass. Medical School on other programs to improve the clinical skills of students are interested in incorporating the DDSPs into their curricula.

(3) Because some of the 70,000 people with mental retardation and developmental disabilities who live in the community have had

difficulty when seeking emergency care, the Emergency Room Support Project was conceived to promote the best standard of medical care and service for people with developmental disabilities seeking treatment at local hospital emergency rooms, by creating a better understanding of the needs of these health care consumers. The grantee, Horace Mann Educational Associates, Inc., conducts outreach to six hospital emergency services to provide inservice facilitation for nursing and paraprofessional emergency room staff. Informational materials for staff of provider organizations who accompany people to the emergency room and support materials for family members about emergency room visits have been developed. Horace Mann will disseminate the project products in order to assist other providers to replicate the project in other regions of the state.

- **REGIONAL DATABASE GOING OUT TO GRASSROOTS**

In 1987 the Council awarded a grant to New England INDEX, to design and implement a Massachusetts Resource Database listing programs in the Commonwealth serving persons with DD and their families. Since then the demand for information and referral has increased greatly, stimulating New England INDEX to apply for additional DD funds to expand access to and use of the Mass. Resource Database by other disability service providers. In 1994 INDEX formed a collaborative network of 10 disability agencies, including ARCs and IL Centers, to design an interactive I&R computer network and to increase information sharing among the agencies. The Lotus Corporation donated its new communications software program "Lotus Notes" to be tested by the Network. The Network has engaged in mutual fundraising to purchase hardware, database software, and the technical support. The system is scheduled to go online in January of 1995.

- **LEGISLATIVE ADVOCACY TRAINING: THE TRAINERS MODEL FOR LOW-INCIDENCE AND MULTI-CULTURAL POPULATIONS**

The Council's legislative advocacy grant conducted three day-long sessions especially designed for organizations which: served people with disabilities as their primary mission; and/or had state-wide or significant regional impact; and/or served a culturally diverse and/or low-incidence population; AND committed to provide at least two trainings later in their community. The third day of training was held at the State House in Boston where participants were walked through the process from filing a bill, to legislative hearings and floor debates, and met with staff of several committees. Information included how to shape an organization's issues, how to implement a campaign, how to mobilize a constituency for action, and how to become an effective presenter.

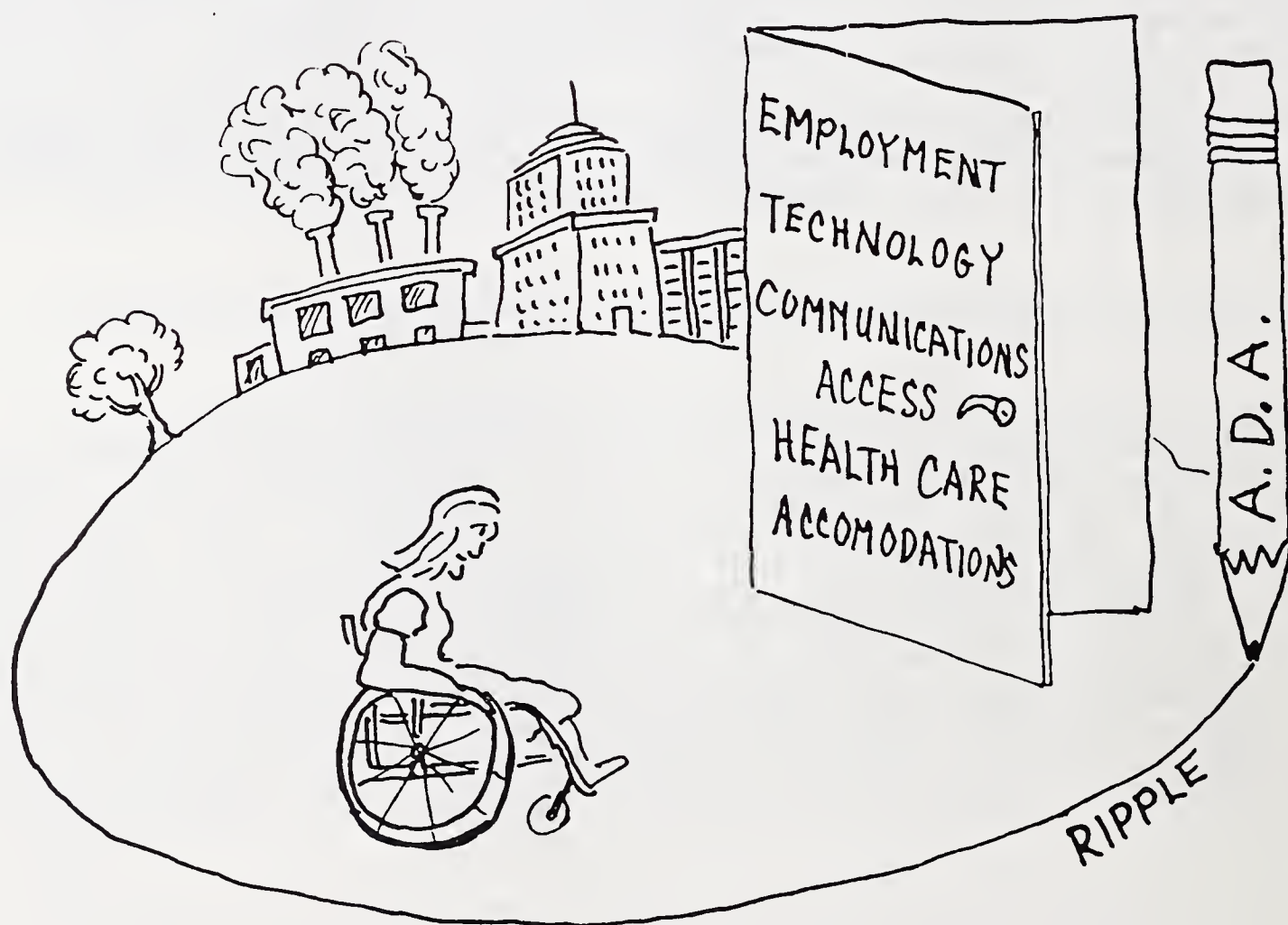
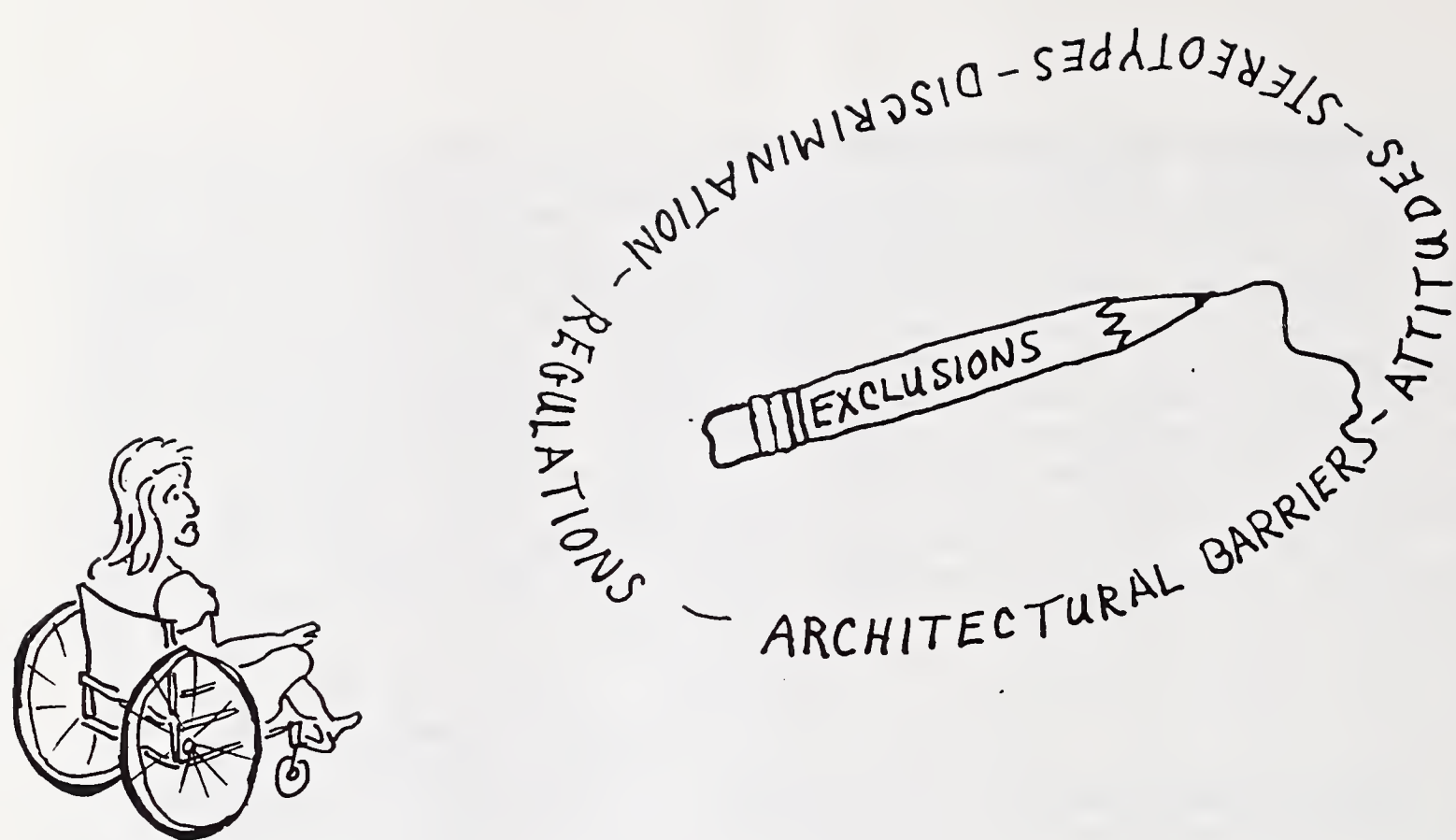
- **"FAMILIES HAVE CHOICES" EVENT**

The Family Support Steering Committee wanted to host or sponsor an event to maintain high interest in the importance of cash assistance, which it had successfully piloted over several years, and to more actively engage families from a variety of backgrounds in the family support movement. Representatives from the Family Supports Steering Group (FSSG) initially consulted with several local providers of human services, representatives of the university affiliated programs and the Boston Region of the Department of Mental Retardation, advocates, and a representative of a family member organization (Families Organizing for Change), about how to educate families about flexible family supports including cash assistance. The planning group eventually also involved representatives from agencies serving various communities of color (Latino, Haitian, and Chinese). "Families Have Choices" in August 1994 was attended by over 100 family members. Supports offered included on-site respite care, transportation (on request), and interpreter/translation services. *(For more information on this innovative event, see Section II.A. #1, above.)*

- **OTHER INNOVATIONS DESCRIBED ELSEWHERE**

* The Council's new "Diversity Policy" & companion "Infusion Plan," in combination with targeted recruitment to identify prospective new Council and committee members from diverse multi-cultural backgrounds, are referenced in Obj. #3, above. The text of the Policy and Plan are available from the office.

* Two activities involving Personal Care Assistance -- a forum for consumers and providers and a research project to examine policy options -- are summarized in Obj. #2, above.



II. C. MAJOR ACCOMPLISHMENTS IN 1994

In FFY 1993 we reported our contributions to the family support movement in general, and our successful demonstration of cash assistance in particular, as our major accomplishment. 1994's work in these areas is described in Objective #1, above. The Council's advocacy with the most visible and immediate impact in 1994 related to a vital human need under multiple and increasing attacks: affordable and accessible housing for persons with developmental and other severe disabilities.

Members of the Council's Independence, Productivity & Integration (IPI) Committee and its Housing Subcommittee and staff co-founded and provided leadership to the Mixed Populations Coalition of the Citizens Planning and Housing Association (CHAPA). The Coalition in 1994 focused on two major areas: the access of younger persons with disabilities to public housing and assisted housing. The Massachusetts Legislature for the third year in a row passed a cap limiting the access of younger persons with disabilities to elder/disabled housing to 10% of occupancy. The Mixed Populations Coalition was successful in convincing Governor William Weld that such a cap was unconstitutional under Massachusetts law, and the Governor vetoed the cap. The Coalition submitted its own preliminary bill to deal constructively with this issue to the Governor, who then formed an inter-secretariat task force to review and advise his office. On Sept. 1, 1994, the Governor filed "An Act to Provide Housing Opportunities to Elders and Younger Persons with Disabilities," much of it based on the original concepts of the Mixed Populations Coalition. Over thirty persons with disabilities, advocates and service providers testified on this bill, which the DD Council had also endorsed. The "Housing Opportunity Bill" (its short name) was reported favorably out of the legislature's Housing and Urban Development Committee on November 29, 1994. The state House of Representatives on December 21, 1994, however, engrossed (passed) its own version, which unfortunately excluded the transitional rental program and funds for service coordination for tenants with disabilities, and prohibited access to these units for individuals with any history of alcohol or substance abuse. Disappointed at the loss of provisions vital for people with disabilities, disability housing advocates worked successfully at the end of the 1994 legislative session to prevent the unacceptable House version from becoming law. The desired earlier version was refiled in 1995.

In the area of assisted housing, members of the Mixed Populations Coalition met with the Massachusetts Housing Finance Agency (MHFA) on its mortgage, rehabilitation loan and service programs. The group's focus has been on developing incentives to private developers to provide scattered site units for people with

disabilities, expanding service coordination to all MHFA funded developments, and to strengthen MHFA's monitoring of compliance of Section IV of the 1992 Community Development Act. A rough draft of the recommendations, completed in December 1994, awaits approval by the membership of the entire Coalition.

Throughout 1994 the Council's IPI staff planner continued her active service on the **Executive Office of Health & Human Services' Special Needs Housing Task Force**. Activities for the last year centered on the institutional facility consolidation process, consumer input in housing policy development, and support for housing service budgets. Much time was spent to encourage passage of the "Facility Consolidation" bill to mandate that funds previously designated for institutional improvement be used for community residential programs. The Task Force also commented on the Executive Office of Community Development's (EOCD) proposed regulations on low-interest mortgages and accompanying EOHHS support services; as of the end of calendar 1994, EOCD is reviewing the comments.

IPI Committee members and staff were also active on the Massachusetts Dept. of Public Health's Family Housing Task Force, which surveyed parents of children with severe disabilities as to their housing and accompanying support service needs. The Task Force's final report will be released in January 1995. Preliminary findings indicate that the major housing problem confronting parents is obtaining funding and information to rehabilitate their present residence for accessibility, with affordable, safe housing a secondary concern.

The Housing Subcommittee of the Council's IPI Committee continued to monitor and influence housing legislation at both the state and federal levels. Nationally, we tracked the developments of HUD's Occupancy Task Force and reviewed HUD's proposed regulations on mixed populations issues, particularly residency caps. Another concern for low-income tenants with disabilities in Massachusetts was the November 1994 statewide referendum question, in which Massachusetts voters abolished rent control. Rents are expected to rise radically in Boston, Brookline and Cambridge (the only communities in Massachusetts which have had rent control ordinances), unless efforts by low-income housing advocates in these three communities to reinstate different forms of rent control protecting vulnerable populations are successful. The outcome cannot be predicted as of this writing (12/30/94), since Governor Weld has indicated that he will most likely veto these petitions. [Later note 1/8/95: A compromise law was enacted and signed on Jan. 3, 1995, the last day of the 1994 session, affording some protections to vulnerable tenants -- i.e. low-income people, elders, and people with disabilities -- for two years. Advocates for low-income tenants were not happy with the outcome, however it postponed what would otherwise have been an immediate draconian impact.]

The Housing Subcommittee also supported the Housing Opportunities in Massachusetts for Everyone (HOME) Coalition, whose legislative platform addressed the housing needs of all the low-income populations in our state. The Coalition's "Home For All" bill, which incorporated the unique housing needs of persons with disabilities and was on the MDDC's legislative platform, failed to pass in the 1994 legislative session. Advocacy was more successful for the "Bond Bill," comprehensive housing finance legislation which did pass. When EOCB issues the bonds, \$25 million of new money will become available for creating housing for elders and persons with disabilities.

For her zealous and sustained leadership with the Mixed Populations Coalition and other housing advocacy, Barbara Chandler, the Council planner who staffed the IPI Committee and its Housing Subcommittee through much of the 1992-94 DD state plan cycle, received a well-deserved Community Service Award from the Citizens Planning and Housing Association in November 1994.

III. REPORTING YEAR EXPENDITURES

This includes Federal expenditures of funds awarded in previous fiscal years. Refer to next page for the breakout.

A. Type of Recipient

	<u>FEDERAL FUNDS EXPENDED</u>
1. State Planning Council	\$352,082
2. Designated State Agency	43,965
3. Other State Agencies	10,000
4. Protection and Advocacy Systems	-0-
5. University Affiliated Programs	-0-
6. Nonprofit Private Agencies	971,179
7. Others	-0-
Total Federal Expenditures	\$1,377,226

B. Cost Category

	<u>FEDERAL FUNDS EXPENDED</u>
1. Federal Priority Area	
a. Employment	\$289,005
b. System Coordination/Community Education	692,174
c. Child Development	-0-
d. Community Living	-0-
2. State Priority Area:	-0-
3. Analyses in Section 122(b)(5)(B)(i-vii)	-0-
4. 1990 Report Activities (other than in priority areas)	-0-
5. Planning, Coordinating & Administration of Priority Areas	352,082
6. Advocacy (other than priority areas)	-0-
7. Functions of Designated State Agency	43,965
Total Federal Expenditures	\$1,377,226

During FFY 1994
(Paid 10/1/93 - 9/30/94)

<u>FFY 94:</u>	
Planning	
(1100-1703)	34,615
+ (1100-1710)	300,301
Administration	
(1100-1703)	42,305
<u>FFY 93:</u>	
Planning	
(1100-1703)	1,106
+ (1100-1710)	16,060
Administration	
(1100-1703)	1,660
<u>TOTAL PAID:</u>	
Planning	352,082
Administration	43,965
Total (1):	396,047

<u>Employment</u>	
FY 92	28,000
FY 93	79,384
FY 94	181,621
	289,005
<u>Systems Coordination/ Community Education</u>	
*FY 92	155,969
FY 93	265,359
FY 94	270,846
	692,174
<u>Empowerment</u>	
FY 92	-0-
FY 93	-0-
FY 94	-0-
	-0-

<u>Other State Agencies</u>		
<u>FFY 92</u>		
U Mass Medical Center	10,000	System Coordination
Total (2) (FFY 92 only)	10,000	

<u>Nonprofit Agencies</u>	
FFY 92	173,969
FFY 93	344,743
FFY 94	452,467
Total (3)	971,179

<u>TOTAL OF TOTALS 1,2,3</u>	
(1)	396,047
(2)	10,000
(3)	971,179
	\$1,377,226

IV. STATE ACTIONS with respect to ICFs/MR during 1994

The 1994 reauthorization of the federal DD Act (P.L. 103-230), like its predecessors, asks for "a description [in the Council's annual report] of the Council's response to significant actions taken by the State with respect to any intermediate care facility for the mentally retarded in such State . . ." Pursuant to the DD Act, the DD Council receives and reviews copies of DPH's survey reports, statements of deficiencies obtained therein, and plans of correction. For the reasons noted below, however, the Council does not involve itself directly with oversight of ICF/MR facilities and programs.

The most significant single action taken by the Commonwealth was reported last year. May 25, 1993, marked the end of direct federal court oversight of the well-being of (on that date) some 2,300 individuals living in large ICFs/MR and some 3,700 people residing in a variety of community programs. Judge Joseph L. Tauro's May order dissolved all prior orders and ended the Court's active involvement in the five mental retardation consent decrees which first began in 1972; he specified in a single order all the obligations of the state and the enforceable rights of the class members. The final order also terminated the independent but state-financed Office of Quality Assurance, earlier established by Judge Tauro to monitor the provisions of the consent decrees, which in some respects exceeded the standards in the ICF/MR regulations. In response to concerns of consent decree plaintiffs, faced with the loss of OQA's specialized monitoring and advocacy for class members, Governor William Weld issued an executive order creating the Governor's Commission on Mental Retardation.

This new body, charged to work cooperatively with consumers, their families, concerned citizens, the Department of Mental Retardation and other agencies to improve the mental retardation system, opened its doors in late October 1993. In its challenging role of system-wide advocate for the interests of all people with retardation in Massachusetts (not only the class members, but also the many thousands of other present and prospective DMR clients, plus other persons with retardation who may have or seek other connections to the Commonwealth), its 3.5 staff and nine gubernatorially-appointed members have been looked upon to troubleshoot individual and group problems not resolvable through usual processes, to review the quality of services and public policies as they affect all persons with mental retardation, hold public hearings, "support" DMR, and periodically make recommendations to the Governor.

In its first year, the Commission met almost monthly and also conducted two major well-attended public hearings, one to elicit ideas for meeting the needs of people on DMR's "waiting list," and one on ways to provide services to persons with challenging behaviors or medical needs. As the result of ongoing complaints

regarding the Fernald State School, Commission staff and members have conducted monthly monitoring visits to ensure that corrective actions are being implemented. In addition, as required by executive order, the Commission completed two reports analyzing the complaints submitted to Commission staff during the past year. A vocal minority of Commission members and attendees at monthly meetings has urged use of DMR's "state schools" (all ICFs/MR) to house people on the waiting list, though this is not a position espoused by the public at hearings. A report will be available in January setting forth the three major recommendations made at the hearings: (1) DMR should develop a strategic plan to reduce a specific percentage of the waiting list within specific timeframes; (2) the legislature should ensure that DMR's annual appropriations are linked to the federal revenues it generates because DMR needs to expand its financial base in order to expand services; and (3) DMR should support a "family-to-family" information/linkage "chain" bringing together persons and families on their waiting list and giving them the means to share ideas and develop and use a variety of resources to meet their needs.

There have been no closures or consolidations of DMR institutions since the closing of the Belchertown State School in December 1992 and the Foxboro campus of the Wrentham State School in 1993. The Governor's January 1994 budget included a provision -- unexpected because not included in his earlier "Facilities Consolidation" recommendations -- calling for the closure of the small Glavin facility; protests from both parents and state employee unions quickly killed this proposal. Following the consolidation plan, the Berry Center has significantly phased down (though it has not formally closed)

Closure of the Dever State School (called for in the plan) is on hold for two reasons: first, the new "Pacheco law" requires the state to take numerous steps prior to privatizing state services; second, new outside language in the state's 1995 budget prevents DMR from reducing either the client census or the staff numbers at Dever and several other facilities. Advocates for a dozen clients at Dever and one at Glavin filed a lawsuit in federal district court alleging that the outside budget language violated their civil right to live in the less restrictive settings called for in their individual service plans; the case is pending as of 12/94.

A new facility, a specialized program at the Fernald State School certified as a nursing home, opened in 1994, with staff trained both in geriatrics and mental retardation. While some other states have similar facilities, this is the first in Massachusetts.

Reportedly DMR's transfer of its 81 community ICFs/MR from ICF/MR funding to Home and Community Based (HCB) waiver funding was effectuated smoothly. Funding under the waiver allows for a more community-focused model of service provision and more individualized consumer-directed supports, while enlisting federal financial participation for those persons who have a high level of need for support (especially medical), liberating the use of state dollars for people who are more independent.

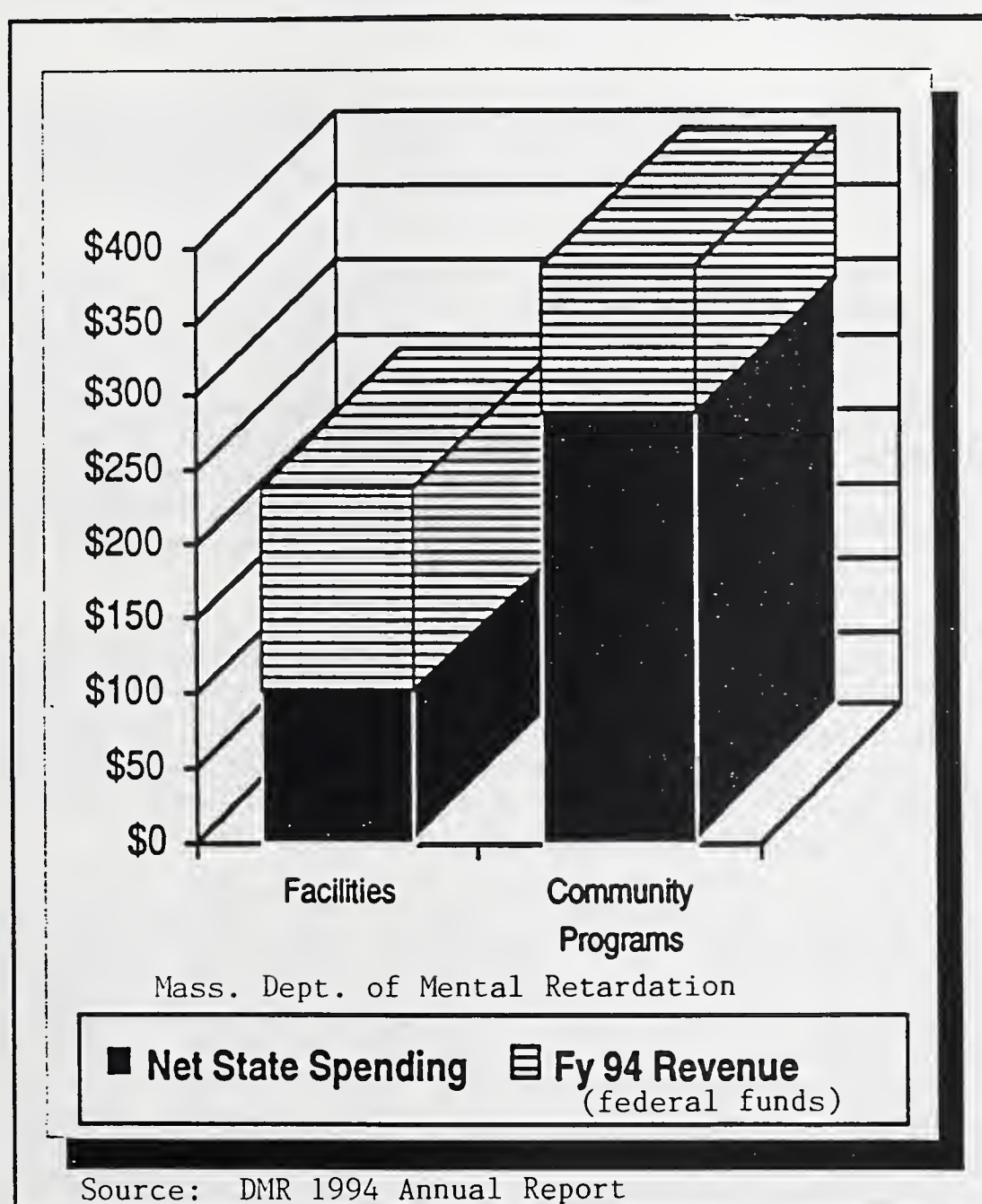
With the transfer complete, the only remaining ICFs/MR in the state are seven large facilities which serve approximately 2,183 (down from 2700 two years ago) of the total 22,000 people who are in some way assisted by DMR. The agency in Massachusetts that continues to have the authority and responsibility to certify facilities to participate in the ICF/MR program is the Mass. Department of Public Health, Division of Health Care Quality, which conducts certification surveys and independent professional reviews on an annual or more frequent basis as needed. The "active treatment" ratings for the seven Massachusetts facilities ranged from 60-90% in 1994, a change from the 92-100% overall ratings in 1993. Decertification of the Fernald State School was threatened mid-year; after a three-month conditional certification was given following correction of deficiencies the facility was certified in August 1994. All seven facilities were certified as meeting the standards of the federal Health Care Finance Administration (HCFA) by the end of calendar 1994.

Beyond the above observations on major developments, it is complex to respond to the DD Act's request for comment on "the Council's response to significant actions taken by the state with respect to ICFs/MR . . ." Our comments from this point will echo those of previous years. On the one hand, the Council has never been a key actor in the lengthy and complex drama enacted since the early 1970s and ending (in some respects only) in May 1993. That drama starred the Commonwealth as defendant (lead player: Department of Mental Retardation) and six parent organizations as plaintiffs. Well-articulated but very differing points of view have been held for nearly twenty years by the numerous parties to the six mental retardation federal court consent decrees, during which time DD Council members have generally directed Council resources elsewhere. (The defendant-plaintiff differences manifested themselves in mid-1993 over the selection of members for the new Governor's Commission, and they continue to influence the group's deliberations. The judge's final order required that three of the nine members had to be appointed from a list submitted by the Advisory Panel to the court's Office of Quality Assurance.)

Another reason for the Council's relative non-involvement is the fact that the ICF/MR program as designed and implemented in Massachusetts is not open to persons whose disability does not include mental retardation (with the exception of some longterm institutionalized class members who -- people later realized after assessments became more sophisticated -- were not retarded); now, of course, it is no longer a model in use in the community. A third reason has been the large number of active participants, overseers and monitors (DPH, DMR, plaintiffs, until recently the court and its monitors, and now the Governor's MR Commission). In the future the ICF/MR model will play a decreasing role in terms of the numbers of clients it serves, and as a percentage of DMR's and Medicaid's overall expenditures on behalf of DMR clients.

Despite our non-involvement with ICFs/MR per se, the Council's public policy position has consistently been to promote options for community living and to point out the system-wide inequities

resulting from the longstanding domination of the large institutional ICFs/MR: despite the relative downsizing of ICFs/MR and the dwindling portion of DMR's clientele they serve, they continue to absorb disproportionate resources. The Council's 1990 report, Creating Open Communities, addressed in detail in Appendix 6 the matter of Massachusetts' allocation of resources in its mental retardation system in the mid and late 1980s and early 1990s. Any reader interested in this topic is encouraged to read the above report, and/or the DD Council's 1989 annual report, which discussed ICFs/MR and related matters in some detail; many of our analyses and comments written in earlier years -- notwithstanding the December 1992 Belchertown closure, the end of federal court oversight, and the conversion away from community ICFs -- remain key to understanding the current political and fiscal dynamics. (Please contact the Council office for copies.)



V. THE STATE PICTURE IN 1994

Section II of this report described the Council's decisions about the use of its own resources, and Section IV discussed DMR's ICFs/MR and related matters. In this section of our annual report, we note some other developments and decisions in Massachusetts that were not directly related to DD Council or ICF/MR activities but that had impact on the lives of people with developmental and other severe disabilities. Since nearly every decision regarding the allocation of public resources impacts the DD population, our comments following are impressionistic rather than comprehensive.

We urge the reader interested in relevant social issues also to consult our 1994 DD state plan, Putting the Pieces Together, available from the office, and the new 1995-97 State Plan, Righting the Scales for Persons with Disabilities and Their Families.

V. A. OVERALL TRENDS

Unfortunately the Commonwealth's third year of fiscal stability continued to come at the expense of the politically vulnerable poor, who remain victims of prior years' reductions in eligibility for the state's public welfare program, in housing rental subsidies, and in availability of affordable quality child care and health coverage. Many people with disabilities are poor, and rely on these and other traditional "safety net" social programs. Both the executive branch and the legislature share responsibility for the decisions made, with all parties including the public seeming to want more while paying for less.

People with disabilities also rely on disability-specific programs. Overall -- with the notable exception of early intervention -- we sense that resources are frozen, if not declining, in relation to need. There are increasing delays in accessing services and/or fewer services actually offered, e.g. for vocational rehabilitation or respite or other family supports.

In connection with our preparation of a new state plan for 1995-97, we were told repeatedly that -- despite DMR's commendable thematic emphasis on family supports -- families wait, often for years, for modest assistance, while respite services for families whose children have physical disabilities and/or complex medical needs, and/or who need out-of-home respite, are harder to come by. More generally, DMR's waiting lists have grown; figures are set forth in V.B., below. Disability advocates felt they spent much of a third year in a row trying to protect the personal care attendant program administered by the state medicaid agency.

Housing trends in Massachusetts mirror what is happening nationally with the US Dept. of Housing and Urban Development (HUD). The Commonwealth is significantly retreating from providing affordable housing in both the public and assisted arenas. The Mass. Rental Voucher Program, which went into effect in 1992, is an attrition effort: each year fewer people are covered. There is a shortage of accessible and/or affordable studios, one bedrooms and multi-bedroom units. While any decrease in affordable housing will affect all low-income individuals and families, its impact will hit persons with disabilities the hardest. (See Section II. C., above, for a description of the Council's and other housing advocates' work during 1994.)

HUMAN SERVICES



It is too early to know what impact the recent changes in the composition of the U.S. Congress will have on disability interests in Massachusetts. This state's voters, unlike their counterparts around the country, returned to office every major state official and member of Congress who sought re-election, while adopting a new term limit provision. The high level of Congressional and gubernatorial concern about "unfunded mandates" -- which are described as including not only social welfare programs but also major disability laws, programs and services such as the Americans with Disabilities Act, the Individual with Disabilities Education Act, job training programs including vocational rehabilitation, and the like -- could result in major changes ahead. As noted above, we observe the "unfunded mandate" phenomenon increasingly manifested at the state level, e.g. serious underfunding of DPPC's protective services, access to courthouses, interpreters (both for foreign languages and for persons who are deaf or hard of hearing) in courts, slow implementation of the landmark 1993 Education Reform Law, state-assisted health insurance cut-offs, waiting lists, etc.

V. B. UNSERVED AND UNDERSERVED GROUPS

In our "1990 Report," Creating Open Communities, we identified a number of groups of people with developmental disabilities that are un- or under-served by publicly supported programs. While circumstances will have changed for a limited number of individuals, the disability populations' overall situations remain substantially as they were five years ago, though the numbers of un- and under-served are larger as the result of cuts in "generic" "safety net" social programs (as referenced in the section above). We again reproduce the charts developed for Creating Open Communities at the end of this section, cautioning that details may have changed but believing that the charts still present a generally valid and useful overview of who is un(der)-served and why.

• PERSONS WITH MENTAL RETARDATION

The Arc Massachusetts, a statewide advocacy group, reports that, despite some modest budget victories in 1994 (\$4.4 million for the "Turning 22" program, and \$2.3 million for "older unserved" and "respite care") the unmet needs of individuals with mental retardation and their family caregivers continued to grow during the mid-1990s:

- * Over 900 adults with mental retardation living with elderly (and frequently disabled) caregivers who are over 65 years of age, are in need of services;

- * Hundreds of families do not receive adequate respite care or other forms of family support;

- * Almost 300 students who reach age 22 each year (losing their entitlement to special education at that age) begin their 23rd year with no provision for continued schooling or other support;

- * State funds have not been allocated to benefit direct care staff for state-funded private sector programs, which support thousands of persons with mental retardation in a variety of community settings.

The state's Dept. of Mental Retardation reports that its waiting lists (for un- and under-served) are up from the recent years' figures of 3,000+ people, to a figure approximating 4,000. The figures, shown below, reflect persons who have approached DMR with a request for services and have gone through their intake procedure and been determined eligible; they do not include people who have not made formal application (whether due to frustration or lack of information), nor persons whose developmental disabilities do not include a clear diagnosis of mental retardation. (DMR is created to serve persons with mental retardation who may or may not have additional disabilities, and it frequently though not invariably

determines that individuals with autism are eligible for its services. It has no statutory mandate and no resources for persons with other developmental disabilities, with the limited exception of the "DD" respite program it inherited from another state agency.) DMR's waiting lists showing figures by local area and region, and are available upon request to the Department's central office: the figures include caregivers/households awaiting respite and other family support services, as well as individuals with mental retardation awaiting specific day and/or residential programs as listed below. The figures in parentheses are a subset of consumers whose primary caregiver is over 60 years of age; a modest appropriation of \$3 million in the 1994 departmental budget for this population enabled DMR to serve 431 persons from this earmarked fund. DMR separately records persons eligible for Turning 22 services, and also now records the growing group of consumers (as distinct from caregivers) who are over 60 years old!

Unserved (report dated 12/19/94); unduplicated statewide count:

Consumers awaiting both day and residential services:	376	(145)
Consumers awaiting (only) residential services:	1937	(949)
Consumers awaiting (only) day services:	399	(98)
Total	2712	(1192)

Underserved (report dated 12/19/94); unduplicated statewide count:

Consumers awaiting both day and residential services:	162	(11)
Consumers awaiting residential services:	893	(281)
Consumers awaiting day services	348	(29)
Total	1403	(152)

Each year, approximately 450 people with mental retardation who are turning 22 and graduating out of locally funded chapter 766 special education programs are referred to DMR for leadership in "transitioning" into the adult service system. Funding constraints since the inception of this program -- which is not an entitlement to services -- in the mid-80's have resulted in lengthening Turning 22 waiting lists: in November 1993, DMR reported 1052 unserved, and 274 underserved, in this age group. In December 1994 these numbers had grown to 1320 unserved, 359 underserved. The current numbers of consumers over 60: 125 unserved, 321 underserved.

DMR's situation was made harder due to a \$14 million dollar deficit in fiscal 1994, caused largely by increases in state employees' salaries which DMR and other agencies had to pick up in their own budgets. At midpoint in state FY 1995 DMR is facing a \$9.8 million shortfall, and hopes that a supplemental budget will pass restoring some or all of this in January 1995.

- **PERSONS WITH CHRONIC MENTAL ILLNESS**

The Alliance for the Mentally Ill of Massachusetts, a statewide advocacy group, reports that while serious mental illness does or will affect one in every four American families, publicly-financed services are shrinking, the failure to enact comprehensive universal health reform means many people remain un- or inadequately covered for basic mental as well as medical health care needs; in addition, there are now over 2,000 homeless mentally ill people in the Commonwealth. The state's Dept. of Mental Health experienced unexpectedly high costs of certain newly-privatized in-patient services in metro Boston toward the end of the year, causing renewed criticism of its reduction in the number of state hospital beds and related increased reliance on the private sector.

- **PERSONS WHO ARE HOMELESS**

The Boston Globe on 12/28/94 reported that the capital's homeless population increased by 10% over last year's (5299 this year and 4809 in 1993), according to the city's annual December homeless census. The director of the city's Emergency Shelter Commission said that inter-city comparisons are difficult because other cities do not conduct a similar census, however a survey by the US Conference of Mayors showed an average increase of 17% in requests for emergency shelter and a 21% increase nationwide in requests by families. Family requests in Boston increased by 15.3% increase over last year; children represented the single largest subset of the homeless population, increasing to 13.4% of the total. An earlier article (Globe, 12/12/94) reported that Christmas in the City, a charitable group that sponsors a holiday party for homeless children, found that the numbers of homeless children grew by 27.3% in Boston in the past year, to 1,018.

On the plus side, the City of Boston and six Boston organizations learned in late December that they have separately received significant federal funds to combat homelessness.

For the past three years the Mass. D.D. Council has consistently advocated for access to public housing for persons with cognitive disabilities. Our advocacy included cross-disability coalition-building as well as singular efforts to make the programs of the Mass. Executive Office of Communities & Development (EOCD) and the U.S. Dept. of Housing and Urban Development (HUD) responsive to the needs of this group. (See II.B., above.) Persons with cognitive and emotional disabilities, as well as growing numbers of families with minor children and working adults, are numbered among the homeless population.

- **MINORITIES AND PERSONS WITH LOW-INCIDENCE DISORDERS**

Minority populations are generally un- or under-served, or -- in some instances -- offered services which are not culturally appropriate. Kindly see our discussion of these issues in the 1994

DD State Plan, pp. 102-104, and a summary of the DD Council's recent work in II.A., Obj. #4, above.

Low incidence populations are frequently un- or under-served, for a variety of reasons, including public and professional ignorance regarding the disease or disability. Our 1992-93 publication entitled Low-Incidence Disabilities describes a number of such disabilities and the groups which represent them. Kindly contact the Administering Agency for a copy: 617/727-4178.

- **PERSONS WHO ARE MINORS OR ADULTS WITH COGNITIVE DISABILITIES, AND LIVING WITH PARENTS OR OTHER FAMILY CAREGIVERS, WHO NEED PERSONAL CARE ATTENDANT SERVICES THROUGH MEDICAID**

The situation changed little in 1994 from what it was the previous year: Medicaid-eligible individuals in the above categories argue that they have medical needs for personal care attendants, while Medicaid believes that existing caregivers in the home can and should perform the service. Generally, the adult with a physical disability living independently will be found eligible for the service, whereas a child or teen in a family or an adult with a cognitive disability living with a caregiver is turned down. Given the undue stress and burden that lack of access to outside sources of personal care puts on parents/siblings/spouses and other caregivers, we include people seeking but not receiving PCA services in the un(der)-served category.



WHO'S OFTEN UNSERVED? (left out)

	Inadequate Resources	WHY? No responsible state agency	Considered "Hard to Serve	Can be very expensive	Comments
• Persons needing outpatient mental health services who are not "chronically mentally ill"	X	X			DMH's focus on CMI has detracted from commitment to this group; 6-7000 on lists and unserved.
• Deaf persons needing outpatient mental health services	X				Fall '89 cuts hurt 80 persons.
• Persons wanting accurate, personalized information and referral		X			ICID does excellent job but system overall does not have info. capacity.
• Persons wanting interagency case management/service planning		X			OFC helps some kids, and Turhing 22 some young adults. No agency for adults.
• Persons needing legal assistance with disability or benefits related problem	X	X			DLC and legal services agencies help many but overall resources inadequate to meet needs. More demand due to 1992 housing and welfare cuts.
• Persons needing guardianship or other legal-protective service but without family member/friend to provide service		X			
• Persons turned down by DMR as "not retarded enough" and/or by DMH as "not MI enough," and/or by ILC as "not capable of self-direction"	X	X	rarely	rarely	
• People with "hard to manage" behaviors of whatever origin (MI, HI, autism, Alzheimer's)	X	X (sometimes)	X	X	
• People awaiting drug and alcohol addiction treatment	X				Serious overall shortage of treatment programs. Far fewer for women, especially pregnant women and those with children.
• People in need of interpreters for ASL or other languages	X				
• People without homes	X	X			6,000 homeless people in state. Est'd 40% with MH or substance abuse problems. Growing number of children.
• Groups who traditionally have less access and service from the public sector, e.g.: —minorities in general —immigrants/refugees and others not fluent in English and from different cultures —Native Americans —Persons in rural areas	X	X (often)			Discrimination, poverty, and inadequacy of specially trained professionals all mean fewer resources directed to these groups. Recent DMH cuts hurt ethnic minorities very badly.

[continued on next page]

WHO'S OFTEN UNSERVED? (left out)

WHY?

Inadequate
Resources

No responsible
state agency

Considered "Hard
to Serve"

Can be very
expensive

Comments

• Persons with low-incidence disorders		X (often)	X (some)		Diagnosis sometimes wrong or difficult.
• Persons with head injuries	X		X (some)	X (some)	MRC Statewide Head Injury Prog. (SHIP) is "Lead Agency".
• Adults with physical or medical disabilities who need housing with supports	X	X			
• Children in need of Early Intervention	X				Fiscal crunch threatens to remove from eligibility those "environmentally at risk"; 25,000 now eligible. Serious staff shortages.
• Children born to drug-addicted or alcoholic parents	X	X		X	
• Children with AIDS or HIV infection	X		X	X	Nearly all are or will become developmentally disabled.
• Families needing medical respite	X	X	X		
• Families needing behaviorally oriented respite	X	X	X		
• Families needing respite	X				
• People turning 22 and awaiting adult services (disabilities include deaf-blind, physical, medical, as well as "regular" MR and MR plus-other-disabilities)	X		a few	a few	Overall wait list now approaching 1900, per Bureau of Transitional Planning (EOHHS).
• Persons with mental retardation on DMR waiting lists (three lists):	X				Total #s are approaching 6000.
• community services				a few	
• Turning 22 (with DMR as lead agency)					
• respite for families with developmentally disabled member					
• Persons on numerous MRC waiting lists	X				Many will make economic contributions if trained and supported for work.

WHO'S (SOMETIMES) INAPPROPRIATELY SERVED?

WHY?

• Persons with disabilities in the correctional system (courts, DYS, DOC) • Persons with disabilities in adult nursing homes but not requiring nursing home level of care	Few specialized services, shortage of staff Slow implementation of OBRA-87 community services development requirements. Special problem for disabled persons who are not mentally retarded or mentally ill — EOHS has not assigned an agency for planning and service development.
• Persons in adult nursing homes in need of "active treatment" • Young adults over 22 in pediatric nursing homes • Young adults over 22 in public health facilities (e.g. Mass. Hospital School) without day programs or community options	Resource and planning problems; shortage of qualified staff. Planning failure — population identified since late '70s and needs well known. Options limited by inflexibilities of Medicaid to pay for services in community which it does cover in institutional settings.
• Persons with mental retardation in large Intermediate Care Facilities (DMR state schools) who do not require ICF level of care	Delayed implementation of consent-decree-required community placements. In some cases, family opposition to community placement. Overall failure to plan beyond "consent decree compliance" despite community living potential of many residents.
• Persons in Medicaid-financed day habilitation and sheltered workshop programs who are capable of paid employment	Need more aggressive conversion assistance for facilities and job development capacity to assist individuals. Need more commitment to provide all needed on-going job supports to individuals.
• Students in private residential schools who could be home and in local schools if family and school system had supports they need	Power of private schools as lobbyists. Fiscal "encouragement" to Local Education Authorities for residential placements. Lack of clear state policy to support children and families in communities and neighborhood schools.
• Persons with severe behavioral problems (e.g., self-injurious, dangerous to self or others)	Some are exposed to aversive "treatments"; others are inappropriately in psychiatric facilities. Earlier interventions and supports are needed to families, schools, and community providers.
• Children in foster care needing permanent family ties	Lengthy legal delays and court backlogs to free children for adoption.
• Persons in DMH hospitals selected for community living	Group homes ready; no staff available.
• Persons with mental retardation in DMH hospitals who do not meet mental health commitment standards	Approximately 200 remain. They have been identified and assessed and are awaiting transfer to mental retardation programs.

V. C. RESOURCE AND FUNDING PRIORITIES

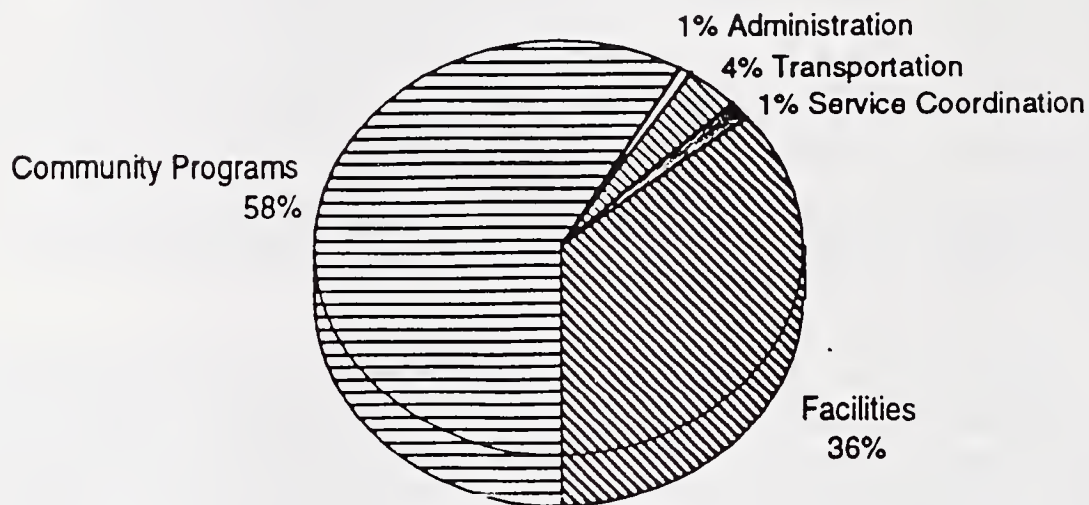
Clear beneficiaries of a reallocation of public resources at the close of calendar 1994 were state legislators, who with the Governor's support voted themselves a 55% raise in salaries, judges who will also get a raise, and persons who will benefit from the legislature's newly-enacted reduction in the state's capital gains taxes. Others who will benefit in coming years will be some elders and people with disabilities who will obtain housing assistance as the result of the passage of a \$35 million housing bond bill.

On 12/22/94, the Boston Globe reported that a valuable new program funded with state dollars, the **Children's Medical Security Plan**, that pays for basic health services for children of low-income families, had grown beyond expectations and would be closed to new applicants on the day after Christmas. Funded by a \$12 million state appropriation and targeted to low-income families not eligible for Medicaid, the popular plan offers free preventive and basic medical care to families whose income is below 200% of the federal poverty level (i.e. \$29,600 for a family of four) or those with higher income who can pay the premiums on a sliding fee scale. Some 21,000 children enrolled, higher than the 15,000 predicted, leading to the closing of new applications.

1993 inaugurated the first capping of the state-funded **CommonHealth** Program, which -- unlike the program described above -- is expressly targeted to persons with disabilities. This two-pronged program, established in 1988 and incorporated in the state's partly dismantled and much-delayed Universal Health Care law, enables working adults with disabilities and families with children with disabilities to purchase affordable non-discriminatory insurance to cover their health care needs. In 1994 CommonHealth was cut by \$654,000, or 123 slots. Since there was no provision to grandfather current enrollees, some people with disabilities who cannot meet the 40 hour a month work requirement will be without the health care they need.

DMR's successful expansion of its **Medicaid home-and-community-based waiver** to cover costs of persons served in community settings, and the resulting transfer of former community ICF/MR group homes to waiver-financed home and family programs, continues the slow but real shift of public dollars from supporting institutional models to supporting smaller programs. The chart on the next page, from DMR's FY 1994 Annual Report, shows that it expends proportionately more on community than on institutional services, though federal reimbursements for facilities remain very high. Note that of the 22,000 persons whom DMR assists in some manner only fewer than 2200 live in the large facilities. (See also Section IV., above, for more detail on ICFs/MR.)

DMR FY94 Spending by Category



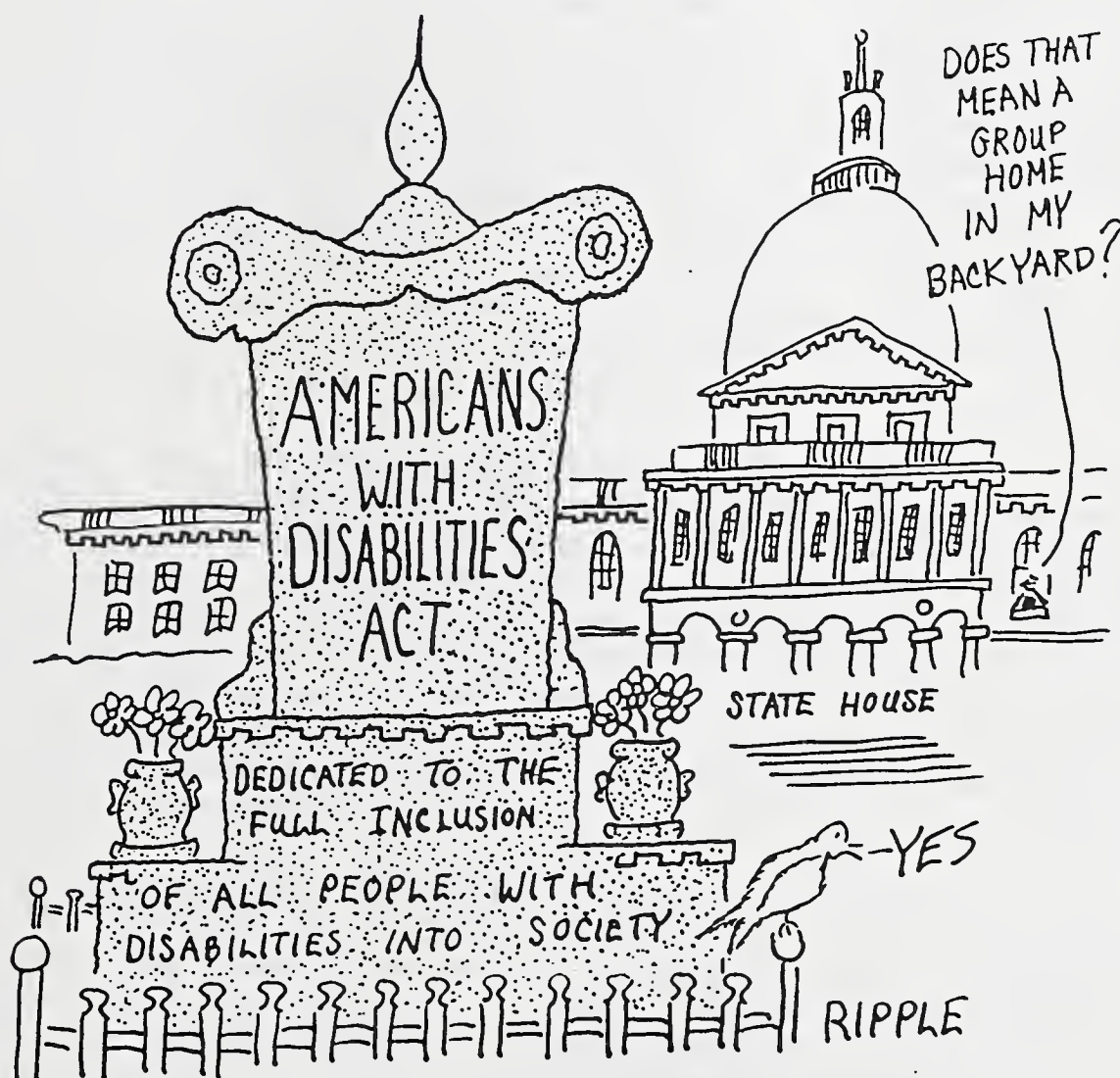
☐ Administration
 ☒ Transportation
 ☒ Service Coordination
 ☒ Facilities
 ☒ Community Programs

Expansion over the course of 1994 in the state's **Early Intervention (EI)** programs was due to increased state dollars, more billings to private insurance and medicaid, and increased federal funding through Part H of IDEA. The Dept. of Public Health (DPH) anticipates that the program will be able to serve 85% of the eligible birth-age three population next year. Massachusetts, a leader in offering early intervention services since the 1970's (with significant DD Council support during those early years) remains progressive in that it includes children at environmental risk as eligible for the program.

Unfortunately services for adults with disabilities experiencing **abuse or neglect** are not expanding, even though the complaints grow in number. The Disabled Persons' Protection Commission (DPPC) was established in 1987 to receive reports of and to investigate reports of abuse, to ensure that appropriate protective services are provided, and to educate the public about reporting requirements. The DPPC received over 3400 reports last year (an average of 300 a month); the number of reports has been increasing steadily since 1987. Of these, approximately 70% of the reports are screened in for investigation: of that number, abuse is indicated in approximately 50-55%. The predominant disability for which abuse is reported and substantiated is mental retardation, with over 75% of all reports coming in involve people with this disability. Although other state agencies (primarily DMH, DMR, and MRC) conduct investigations for the DPPC (as well as for their own purposes), insufficient staff at DPPC -- compounded by a 7%

reduction in its 1994 budget -- results in delays in conducting investigations and reviewing protective service plans.

Another subtle but important shift in resources has resulted from a revision in the focus of the state's Department of Social Services. Despite DSS's intention to preserve and strengthen families, limited resources mean that priority is given to abuse or neglect; this tends to exclude families where children (or parents) are at risk and in need of services because they have disabilities. The Federation for Children with Special Needs got a call from a distraught mother with disabilities who had asked DSS for help in bathing her baby; DSS had told her it could not do this, and she did not know where to turn. DSS and other agencies serving children have worked out agreements whereby the "disability" agencies such as DMR and DMH are to serve these children but no new funding is available for them to do so.



V. D. POLICY REFORM

The state's Dept. of Mental Retardation oversaw several policy reform initiatives in 1994. The most unusual resulted from revelations in The Boston Globe and national media.

"On otherwise uneventful mornings in the early fifties, a group of "retarded" schoolboys gathered for a very special breakfast -- cereal doused with radioactive isotopes. Some forty years later, the question is being asked: What, if anything, was wrong with the meal?"

"The Science Club Serves Its Country," article in Esquire, December 1994, pp. 122-129.

It was immediately clear that this vulnerable population (and some others, including pregnant women) had been selected for their "availability" and the likelihood that they would neither understand nor object. Radioactive tests had been performed at the Fernald and Wrentham State Schools (as well as numerous other public and private hospitals) over several decades, from the 1940s through the 1970s, as part of a widespread national effort to understand the effects of exposure to different levels and kinds of radioactive substances. Nationally the U.S. Secretary of Energy Helen O'Leary opened the government's files on radiation and human testing; in Massachusetts DMR's Commissioner Philip Campbell quickly convened a task force, and charged it to attempt to identify the individuals who underwent the tests, determine their present status, and review records from other facilities to see if similar experiments were conducted there.

The group worked zealously and with emotion and controversy for over three months, producing a 150-page report, later praised by Washington officials, that described what had happened decades earlier. The "good news" was that apparently no significant health risks were incurred by the participants who were found (26 of 74 were not), some of whom testified eloquently as to what happened in the tests as well as what it was like to grow up in an institution in the 1950s; the "bad news" was that individuals' basic human rights had been violated by the failure of academic researchers and responsible state officials to obtain informed consent.

The reader is referred to the article in Esquire quoted above, for a fascinating and frequently disturbing account of the human implications of these tests. Commissioner Campbell writing in DMR's 1994 annual report (p. 9) summarizes the lesson: "The history of the world's treatment of people with mental retardation is a bleak tale that offers an unsettling message for us today. It is true that much progress has been made in the last 20 years to erase stigmas and prejudices. But we must never forget how easy it can be to exploit vulnerable individuals for sinister or even the most benign purposes. These situations must not be tolerated,

and society should make every effort to ensure that they never happen again."

Other DMR initiatives: Overall, 1994 saw the Department continuing to place greater emphasis on family supports, filling its senior staff position for this program after a long vacancy, and working with DPH on a joint family support plan (see next entry, below). An additional 2,060 individuals qualified for services under the expanded Home and Community based waiver, described in IV, above. The new QUEST (Quality Enhancement Survey Tool) system of quality assurance, focusing on consumer outcomes, was initiated in January 1994: 71 agencies had completed the survey and certification process as of September 1994, having gone through a detailed review of the impact of their services on the quality of life of over 1100 individuals receiving a variety of supports and services from them. Concerns about inconsistency of surveyors and delays in agencies' receiving their reports were raised and are being addressed by staff. DMR also significantly increased its in-house capacity both for investigating human rights and other violations, and for providing consumer/family and staff training; each region now has both training units and advisory councils.

The rights of citizens with mental retardation were strengthened by a new law passed in December 1993. Actively supported by DMR and the DD Council, both of which participated in the broad-based task force that met throughout 1992 and 1993 to prepare and lobby the bill, the law facilitates the testimony of persons with mental retardation (who often are victims of crimes or witnesses to them) in the state's courts.

● CHILDREN AND FAMILY INTERAGENCY INITIATIVES

The Interagency Policy on Early Childhood Transitions, in effect since 1990 among the state Departments of Education and Public Health (Early Intervention), Executive Office of Health and Human Services, Head Start (federal), and the child care community to promote the movement of very young children (from early intervention, most often) into the educational system, was recently revised to require that a child who turns three in late spring or summer in an EI program (and who is eligible for special education services) must have an Individual Education plan developed by the child's school district in place, with special education services provided by the school district in accordance with the IEP, commencing on the child's third birthday.

In a related development, EOHHS Secretary Charles Baker directed DMR and DPH to plan jointly for a coordinated approach to delivering family support services, in anticipation of the passage of the "Family and Citizen Support Bill." DPH is to assign \$50,000 and DMR \$500,000 to family support services; their joint report was forwarded to EOHHS in late 1994, where it will be reviewed by the new EOHHS secretary, Gerald Whitburn, who begins his duties on January 3, 1995.

● MEDICAID MANAGED CARE

Two parallel systems -- one for "regular" health, the other for a separate ("carved-out") mental health and substance abuse [MHSA] component -- have been put in place for several Medicaid-eligible populations beginning in 1992. Recipients with disabilities were the last group to be enrolled: notices sent out in late 1994 advised that individuals who had not yet chosen a primary care clinician (PCC) or a health maintenance organization (HMO) would soon be assigned a provider by the Medicaid agency. The disability community's initial experiences have been mixed: clearly there is benefit where care is better "managed" and coordinated on an individual's behalf; however where people are confused by the enrollment procedures (this has been common), and/or where new restrictions on the providers one can use interfere with longstanding patient-provider relationships or with accessing specialists, or where new limits are imposed on the kinds and duration of treatments offered, there are problems. Medicaid has improved the process based on input from disability advocates: recipients may appeal their assignments, may switch their PCCs once a year for any reason and more often for cause, and may go outside their assigned geographic region if there is a clinical reason to do so.

Other state health developments: With the demise of efforts to enact universal national health coverage, state programs such as Medicaid's managed care, the Children's Health Security Plan, and Commonhealth, will become increasingly important vehicles to enable people to obtain affordable non-discriminatory coverage. The Division of Medical Assistance submitted a request in April 1994 for a "mega waiver" under Section 1115 of Title 19 of the Social Security Act, to test several inter-related and complex hospital and other health care financing and delivery initiatives; at the end of 1994 negotiations are still underway on Massachusetts' application, and companion state legislation will be needed after federal approval is secured. The implications for various disability Medicaid recipients and other disability populations are not yet entirely clear to us. [Because of the many and complicated changes likely to take place in the multi-faceted health care system -- of which the developments in these two paragraphs represent only a few examples -- the Council decided to adopt a new Health Care priority for its own work in 1995 and beyond.]

* PRIVATIZATION

This complex subject has implications far beyond disability services into all reaches of state and federal government. In addition to our comments on the "Do the Right Thing" campaign (see II.A., Obj. #4, above), we note here that generally the state



DIRECT CARE WORKER IN WONDERLAND

administration's policy is to expand the privatization of selected state services on the grounds that government is frequently not a good direct provider and the private sector can be more creative, flexible and responsive, and also that the private sector services can or should cost less. However, the Democrat-controlled state legislature, more responsive to public employee unions, has made it more difficult than in previous years to contract out state services, and no one wants to pay more.

While the administration takes pride in the \$100 million that Massachusetts has put into the private provider system in the past five years, neither the executive branch nor the legislature has targeted wage increases for the estimated 20,000 people working in community homes and day programs, homeless shelters, mental and public health clinics, and similar settings. Public employee union organizers are talking with provider workers, but views differ on whether unionization would bring more rigidity with presumed better pay. Despite a few well-publicized cases of well-paid executives in provider agencies unearthed by the state auditor, we share the concerns articulated by Jane Collins of the Mass. Human Services Council: "Providers are squeezed to the wall. **Direct care workers are making poverty-level wages for their difficult and sometimes dangerous work.** Staffing ratios are down; individualized attention is increasingly hard to come by; waiting lists for services are growing rapidly; and in many other ways the state's neediest citizens are suffering from the loss of necessary services." (quoted in Boston Globe, 11/29/94, p. 53)

*** CARDS: NEW REHABILITATION AND DISABILITY PLANNING GRANT**

The Executive Office of Elder Affairs learned in late fall 1994 that Massachusetts had been awarded a 3-year planning grant from the U.S. Administration on Aging, to enhance service provision for the elders and persons with disabilities. The Coordinating Agencies for Rehabilitation and Disability Services (CARDS) grant will start with a work group of 15-20 people, with subgroups which to inventory various "long term care" programs and services, and focus groups to gather perspectives from stakeholders and analyze strengths and weaknesses of various programs. Federal funds will place staff not only at Elder Affairs, but also at the Mass. Office on Disability, EOHHS, and in a "lead" home care agency. The DD Council had assisted with initial brainstorming around design of the grant, and in supporting Elder Affairs' application.

V. E. ADVOCACY

The 1992 reauthorization of the federal Rehabilitation Act included some positive changes for individuals with disabilities in Massachusetts, as the result of which the Rehabilitation Advisory Committees for both the Mass. Rehabilitation Commission (MRC) and the Mass. Commission for the Blind (MCB) have become more consumer-centered and -driven. The Mass. State Independent Living Council has increased its consumer membership and revamped its by-laws to guarantee more consumer leadership and participation. The downside of the reauthorization is that state and federal vocational rehabilitation (VR) dollars have not matched an increase in consumer VR needs, and more consumer involvement does not directly aid VR clients or other individuals with disabilities in getting jobs. Although the economic recovery of both the state and nation is evidenced by lower overall unemployment, the national unemployment rates for individuals with disabilities is still estimated to be 66%.

• ADA IMPLEMENTATION IN STATE GOVERNMENT

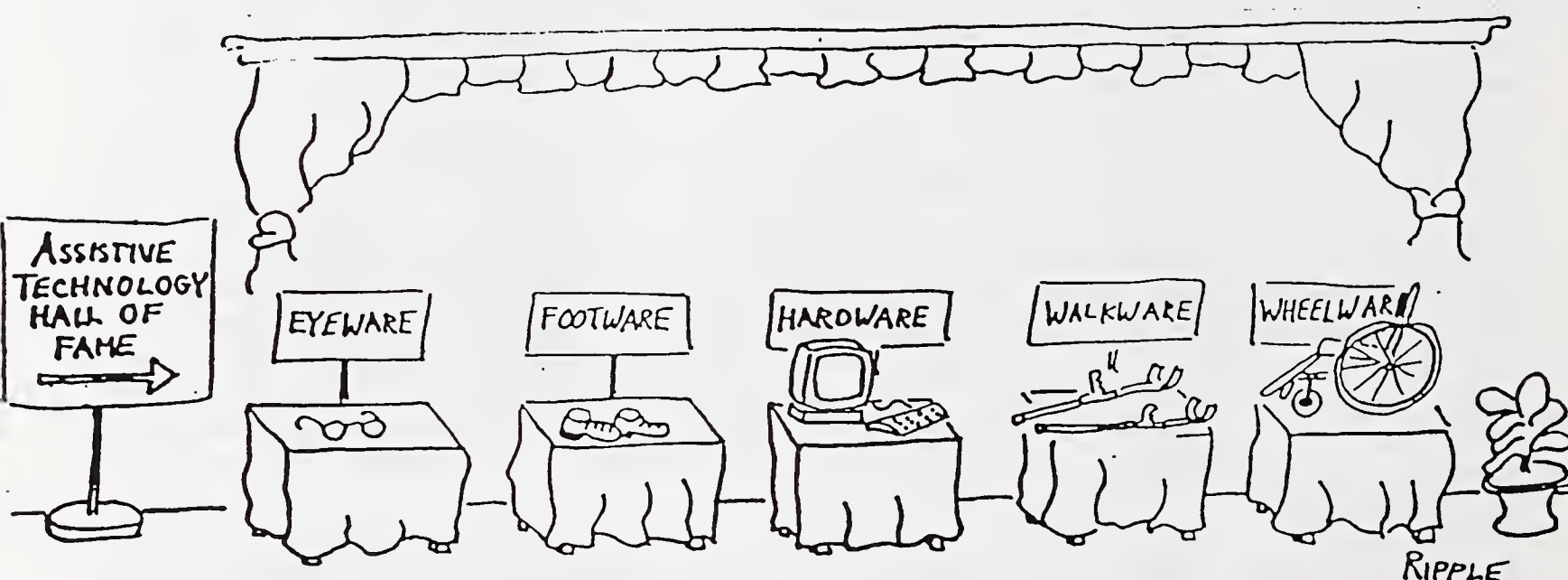
Title II of the Americans with Disabilities Act prohibits state and local governments from discriminating on the basis of handicap. The Massachusetts Office on Disability (MOD) is the lead agency for the implementation of the ADA in state government. MOD conducted training sessions for State Agency ADA Compliance Officers in 1992 and 1993; in 1994 it required an ADA Structural Survey of all state agency occupied locations, and a Title II Non-Structural questionnaire.

Many problems with both physical and programmatic accessibility remain. Much of the State House is still inaccessible. Many of the state court houses and public facilities are inaccessible both physically and programmatically, and change has been slow. Funding has not been available to MOD for its additional responsibilities, in fact the agency's resources have been cut, and appropriations have not been made for other state agencies to make necessary changes. Recently several advocates with disabilities, frustrated after years of negotiations, filed a lawsuit against the Massachusetts Bay Transportation Authority for failure to comply with numerous provisions of the ADA.

A development begun in 1993 and bearing fruit in 1994 was the Department of Personnel Administration's ADA Task Force which, with the active involvement of Council staff, met twelve times to review the state's personnel statute and civil service policies and practices to assure consistency with ADA's requirements. The final report listed both substantive and stylistic changes necessary for the Commonwealth as an employer to be in compliance with the law.

The new Interagency Disability Services Coordinating Council (see "Advice to the Governor," below) studied the requirements of the

little-publicized Section 508 of the Rehabilitation Act, and a resulting state executive order (No. 348, signed in January 1993), requiring that information technology and electronic equipment be accessible, or able to be made accessible, to persons with different disabilities. The state's growing use of "Windows" software poses problems for people with visual and other disabilities. To address the problems, the Mass. Assistive Technology Project and several disability agencies led by Comr. Charles Crawford of MCB started in mid-1994 to talk with the complicated web of state agencies responsible for setting standards and purchasing computer systems, to encourage the Commonwealth's compliance with the law and the executive order. It is too early to report the results of this collaborative educational effort.



• ADVICE TO THE GOVERNOR FROM THE DISABILITY COMMUNITY

We regret that 1994 did not give birth to the disability consumer advisory council, about which we reported last year. In February 1993 Governor Weld at a special disability event had signed an executive order creating a senior advisory council to provide a direct link between the governor and the grassroots disability community. Disability advocates, including several MDDC members and staff, and MOD had for several years prior worked towards such a body, which is charged in the order with taking a cross-disability, comprehensive look at issues impacting persons with disabilities in Massachusetts and the role of state government in helping address them. Volunteers worked in 1993 with MOD to solicit "applications" from persons with disabilities interested in serving on the advisory council, then narrowed the list of 200 interested persons to 50 who would be considered by MOD for referral to the Governor's appointments staff. Though the list of

recommended individuals was forwarded by MOD to the governor's appointments office in 1994, no appointments have yet been made.

Governor Weld also issued a second order charging the senior managers of state disability agencies to mutually examine ways for better coordination and meeting mutual management and information needs. Unlike its consumer counterpart, this body -- the Interagency Disability Services Coordinating Council -- did begin its work in 1994, meeting several times under the direction of MOD, and with active financial and staff support from MRC, MCB, MCDHH, DOE, the DD Council, and others. The agency chiefs educated themselves and developed mission and vision statements, and initial workplans, finding the get-togethers a valuable forum at which to share disability-related interests and concerns such as compliance with Section 508, described above. The Coordinating Council plans to formalize certain positions and make recommendations to the Governor in 1995.

For more information about the Massachusetts Developmental Disabilities Council or the Administering Agency for DD, kindly contact the Council office at (617) 727-6374; the AADD at (617) 727-4178; or either program via TDD at (617) 727-1885, or via FAX at (617) 727-1174.

Massachusetts Developmental Disabilities Council --- MEMBERS December 1993
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Membership changes are
expected soon. Please see II.A.#7.

		Appointment Date	Term Expires
Jane Ambash		10/26/93	10/94
Steve Bachner		10/18/91	10/94
• Jean Moltenbrey	Exec. Off. of Elder Affairs	02/18/93	10/93
Lucie Chansky		10/18/91	10/94
John Chappell, Jr.	Mass. Rehabilitation Comm.	02/18/93	10/93
Sheryl Cole		02/24/93	10/94
Mark Denning		10/18/91	10/94
Michael Dorsey		10/18/91	10/94
Sherry Dottin		10/18/91	10/94
Grayson Emery		10/18/91	10/94
Mary Beth Fafard	Department of Education	01/18/93	10/93
Florence Finkel		02/18/93	10/94
Diane Flanders	Medicaid	10/18/91	10/92
Patricia Freedman	Disability Law Center (P&A)	10/18/91	10/94
Francis Galligan		10/18/91	10/94
James Gleason	Shriver Center (UAP)	10/18/91	10/94
Barbara Gopen	Vice-Chairperson	06/24/92	...
• Lorraine Greiff	Office on Disability	interim.	acting rep.
Inta Hall		10/18/91	10/94
Lynda Hoffman		10/18/91	10/94
Yoang Hoon Jung		06/19/90	10/94
William Kiernan		10/18/91	10/94
Rosemary Larking		10/18/91	10/94
Carmel Nason		10/18/91	10/94
Priscilla Osborne	Institute for Comm. Inclusion	10/18/91	10/94
• Karin Raye	Dept. of Attorney General	? 01/95	
Rogera Robinson		10/18/91	10/94
• June Rowe	Dept. of Mental Retardation	? 01/95	
Edith Schneider		10/18/91	10/94
Gerald Scott		02/18/93	10/95
Howard Shane		10/18/91	10/94
Ruth Berniss Smith		10/18/91	10/94
Robert Sneirson	Secretary	10/18/91	10/94
Jean Tsokanis		10/18/91	10/94
Janet Vohs		10/18/91	10/94
Howard Wayne	Chairperson	11/05/93	...
Suzanne Welch		08/13/93	10/94

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Barbara Chandler, Planner
Peggy Freedman, Planner
Mary Mullen-Miele, Admin. Sec'y.
Deirdre Whelan, Legal Counsel
Jody Williams, Executive Director

Daniel Shannon, Director
Evelyn DiMaiti, Grants Manager
Liz Francher, Program Coordinator
Harold Lieberman, Admin. Asst.

- State agency representatives whose appointments are pending or interim.
- Additional state agency representatives whose appointments are expected shortly.
- The Chair and Vice-Chair serve at the Governor's pleasure.

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PLAN FOR DISTRIBUTION OF 1994 ANNUAL PROGRAM PERFORMANCE REPORT

The distribution of this document, following its printing in January 1995, will be similar to that for our annual Developmental Disabilities State Plans, i.e.:

- * Council and Committee members
- * Members of Massachusetts Legislature
- * Members of Massachusetts Congressional delegation
- * Directors and key staff of disability-related agencies in Massachusetts state government
- * Senior policymakers including the Governor, his staff, and cabinet secretaries overseeing disability-related programs and services
- * Disability planning and coordination bodies in state government (e.g. Statewide Independent Living Council, Interagency Disability Services Coordinating Council, Statewide Advisory Committees to MRC, DPPC, DMR, etc.)
- * Numerous disability advocacy and provider organizations
- * State House Library (and its depositories throughout the Commonwealth)
- * New England DD Councils
- * National Association of Developmental Disabilities Councils
- * Regional and national offices of Administration on Developmental Disabilities, US Dept. of Health & Human Services
- * Mass. DD program grantees
- * Others, upon request

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